THE UNIVERSITY OF QUEENSLAND

AUSTRALIA

An Aboriginal woman's historical and philosophical enquiry to identify the outcomes of prenatal alcohol exposure and early life trauma in Indigenous children who live in Aboriginal communities in Queensland.

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Bachelor of Applied Health Sciences (Indigenous Primary Health Care) Hons

Master of Applied Epidemiology

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The University of Queensland in 2018

Faculty of Medicine

Preface

This thesis describes my research journey over the past 20 years as I have striven to understand the effects that alcohol use in pregnancy has on the health of Aboriginal women and their children and families.

Abstract

This doctoral thesis results from the experiences, findings and interpretation of several research projects that I have embarked on throughout my personal, professional and academic life in the area of alcohol and pregnancy in conjunction with early life trauma. My journey to identify the outcomes of prenatal alcohol exposure and early life trauma in Indigenous children who live in Aboriginal communities in Queensland has spanned the last two decades. During this journey I have discovered an understanding of the links between alcohol and pregnancy and healthy babies. I have been through a series of academic awakenings as well as personal insights. As an Aboriginal woman and student in a vast educational institution, I have had difficulty in separating the academic discovery from the personal.

My approach throughout this thesis consists of four different methods in data collection, I have used participatory action research, quantitative and qualitative methods along with a narrative style explication method that will transfer the lessons that I have learned to the audience or readers, in relation to academic knowledge that I have gained as well as the enormous depth of personal experience. The important process of interacting with the community, developing a two-way form of respect, being included in the community, understanding the value of narratives, the validity in reporting and other qualitative methods has been a valuable experience.

As Van Bronkhorst (2012) points out:

> *"Learning together has the potential to honour the perspective of local communities and different cultural perspectives, and to entail an exploration of the inherent diversity and structural equity issues. Learning together also has the potential to develop an informed community of adults who feel empowered to address the issues of health and well-being in their own lives and to confront a health care system that ignores their informational needs."*

This consideration of their cultural needs is vital to their health and wellbeing. By contextualizing literacy within the health field it addresses the development of discrete literacy skills, and even advocacy for behavioural change which strengthens people's capacity to think critically about information leading to a greater sense of power and

control in their lives. Consequently, this thesis allows for a working definition of Health Literacy:

> *"A model to engage groups in the development of health materials, while at the same time increasing their literacy levels and critical thinking skills to encourage lifelong interest in gaining, sharing and acting upon, health knowledge."*

This investigation explored Aboriginal women's perceptions and experiences of maternal alcohol consumption and the effects on the child. The outcome of this study was the conclusion that alcohol use is linked to a lifecycle of behaviours, and that alcohol use within Aboriginal communities can best be understood in terms of a life-cycle model of drinking behaviours.

Declaration by author

This thesis *is composed of my original work, and contains* no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, financial support and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my higher degree by research candidature and does not include a substantial part of work that has been submitted *to qualify for the award of any* other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

I acknowledge that an electronic copy of my thesis must be lodged with the University Library and, subject to the policy and procedures of The University of Queensland, the thesis be made available for research and study in accordance with the Copyright Act 1968 unless a period of embargo has been approved by the Dean of the Graduate School.

I acknowledge that copyright of all material contained in my thesis resides with the copyright holder(s) of that material. Where appropriate I have obtained copyright permission from the copyright holder to reproduce material in this thesis and have sought permission from co-authors for any jointly authored works included in the thesis.

Lorian Hayes, Candidate

Publications included in this thesis

No publications included.

Submitted manuscripts included in this thesis

No manuscripts submitted for publication.

Other publications during candidature

HAYES, L. 2001. Grog Babies: Where Do They Fit in This Alcohol Life Cycle? Aboriginal and Islander Health Worker Journal, 25, 14-17.

BOWER, C., **HAYES, L.** & BANKIER, A. 2009. Fetal Alcohol Spectrum Disorders Australian Government.

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Book Chapter

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Awards

HAYES, L. International Star Fish Award Foetal Alcohol Spectrum Disorder: Having the courage to make a difference, 2011, 4th International Conference on Foetal Alcohol Spectrum Disorder, Vancouver, British Columbia, Canada,

HAYES, L., Award for the dedication and commitment in raising the awareness, training and education of Foetal Alcohol Spectrum Disorder in the Indigenous communities throughout Australia, Australian Labor Party Foetal Alcohol Spectrum Disorder: 2005, Brisbane, Queensland, Australia

Conference Presentations

Presentations: invited – this includes workshops/seminars/forums

HAYES, L. Foetal Alcohol Spectrum Disorder, Australian Aboriginal Women in Prison. Foetal Alcohol Spectrum Disorder and the Law: A Conversation about Current Research and Practices, 2013 Vancouver, Canada. (Invited presenter).

HAYES, L. Trans-generational Trauma in Foetal Alcohol Spectrum Disorder. 5th International Conference on Foetal Alcohol Spectrum Disorder, Research, Results and Relevance: Integrating Research Policy, and Promising Practice around the World, 2013 Vancouver, Canada. (Invited moderator).

HAYES, L. Improving Cultural Capabilities in Frontline Service Delivery: Ensuring Cultural Appropriateness is Utilized when Delivering Patient Care for Individuals who have been Diagnosed with FAS. 5th International Conference on Foetal Alcohol Spectrum Disorder, 2103 Vancouver, Canada. (Invited presenter)

HAYES, L., O'MALLEY, K. & VAN BIBBER, M. Can Science, Practice and Humanity ever find Common Ground in the Management of Patients and Families with Foetal Alcohol Spectrum Disorder? 5th International Conference on Foetal Alcohol Spectrum Disorder; Research, Results and Relevance: Integrating Research Policy, and Promising Practice around the World, 2013 Vancouver, Canada. (Invited presenter).

HAYES, L. From Stone Age to Space Age: The Impact of colonisation on the culture of Indigenous Peoples from a Foetal Alcohol Spectrum Disorder Perspective. 4th International Conference on Foetal Alcohol Spectrum Disorder, 2011 Vancouver, Canada. (Invited Key Note Address)

HAYES, L. Children of the Grog: Promoting health literacy in deprived social environments in Indigenous Australian Communities. 3rd International Conference on Foetal Alcohol Spectrum Disorder, 2009 Victoria, Vancouver Island, Canada. (Invited presenter).

HAYES, L. Children of the Grog: Promoting health literacy in deprived social environments in Indigenous Australian Communities. Biala Foetal Alcohol Spectrum Disorder Workshop, 2009 Brisbane, Australia. (Invited presenter).

HAYES, L. We can't afford another public health issue; we call this a first world nation. Save the Children Conference, 2009 Kununurra, Western Australia. (Invited presenter).

HAYES, L. Brain Differences; working differently not harder with individuals with Foetal Alcohol Spectrum Disorder. 2007 Portland, Oregon, USA. (Invited presenter).

HAYES, L. Grog Babies: Where do they fit in the alcohol lifecycle? 2nd International Conference on Foetal Alcohol Spectrum Disorder, Research, Policy, and Practice from Around the World, 2007 Victoria, Canada. (Invited presenter).

HAYES, L. Children of the Grog: promoting health literacy in deprived social environments in Indigenous Australian Communities. Australian Paediatric Surveillance Unit Conference, 2007 Sydney, Australia. (Invited presenter).

HAYES, L. Strategies to assist the inclusion of children with Foetal Alcohol and Foetal Alcohol Effects Syndrome into Children's Services. Childcare Access, Resource and Training Agency (CARTA), 2004 Queensland, Australia. (Invited presenter).

Membership

Member, Building capacity for Foetal Alcohol Spectrum Disorder screening and diagnosis through a prevalence study: The Cherbourg Project 2015-2017, Cherbourg, Queensland, Australia, 2018

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Member, International Expert Advisory Committee, 4th International Foetal Alcohol Spectrum Disorder Conference, University of British Columbia Vancouver Canada, 2011

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Founder and Director NICFASEN (National Indigenous Corporation FAS Education Network) Australia, current

Member, National Indigenous Foetal Alcohol Spectrum Disorder Resources Project Reference Group (DoHA), Australia

Indigenous Advisor Foetal Alcohol Spectrum Disorder Australia

Member of the Intergovernmental Committee on Drugs Working Party on Foetal Alcohol Spectrum Disorder, Australia contributed to the Monograph

Member, Expert Group for Assessing Foetal Alcohol Spectrum Disorder Data Collections in Australia (Australian Institute for Health and Welfare), Australia

Senior Consultant, Foetal Alcohol Spectrum Disorder: Development of a Screening and Diagnostic Instrument for Australia (Foetal Alcohol Spectrum Disorder Project)

Member Expert reference Group, Alcohol and Pregnancy and Foetal Alcohol Spectrum Disorder; Resources for Health Professionals working in Aboriginal and Torres Strait Islander health Care Settings, NDRI, Curtin University, WA

Associate Investigator, Foetal Alcohol Spectrum Disorder (FASD): Knowledge and Referral Pathways in Early Childhood Settings, NDRI, Curtin University, WA

Contributions by others to the thesis

I acknowledge the support I have received from my Principal Advisor Prof Wendy Hoy and Associate Supervisor Dr Leanne Coombe for their advice, editing, recommendations, and support with the final restructuring of the thesis content.

Statement of parts of the thesis submitted to qualify for the award of another degree

CHILDREN OF THE GROG: Alcohol Lifestyle and the Relationship to FAS and Foetal Alcohol Effects

Indigenous Health Program, Australian Centre for International & Tropical Health & Nutrition, Faculty of Health Sciences

Submitted in partial fulfilment of a BAppHSc(IPHC) Honours in the Faculty of Health Sciences, University of Queensland, November 1998

What are you drinkin' now?

National Centre for Epidemiology and Population Health Submitted in patrial fulfilment of a Master of Applied Epidemiology, Australian National University, 2001

Research Involving Human or Animal Subjects

I am not able to provide details of any ethics approvals obtained during my research including the ethics approval number and name of approving committees as I was living in Bundaberg during 2011 and this information was literally wiped out by the floods.

Acknowledgements

Acknowledgement to country Aboriginal way

Today we stand in footsteps millennia old.

May we acknowledge the traditional owners

Whose cultures and customs have nurtured,

And continue to nurture, this land,

Since men and women awoke from the great dream.

We honour the presence of these ancestors

Who reside in the imagination of this land

And whose irrepressible spiritualty

Flows through all creation.[1]

Cultural warning

Aboriginal peoples and Torres Strait Islander peoples are warned that the resources, oral presentations and discussions in this thesis may contain images of deceased persons and images of places that could cause sorrow. There is no intention to disrespect.

I offer gratitude to the Indigenous people who carved the trail for the research pathway and the footprints that I have tried to follow. I admire the authors of such a rich source of literature that has enabled me to draw upon throughout my research process.

In submitting this thesis, I offer my respect to Elders past and present of the Aboriginal peoples on whose land I have walked upon, lived and worked throughout the duration

[1] 'Acknowledgement of Country', reader's letter, Koori Mail 469 p.23
Source: https://www.creativespirits.info/aboriginalculture/spirituality/welcome-to-country-acknowledgement-of-country#ixzz5JhUZRdPm

of my research. I acknowledge the lands are a place of age-old ceremonies, of celebration, initiation and renewal, not forgetting that the Aboriginal people's living culture has a unique role in the life of their respective regions.

Firstly, I acknowledge the two (2) traditional nations Guugu Yimithirr Warra (Hope Vale) and Wakka Wakka (Cherbourg) located within Queensland Australia for their warm 'Welcome to Country' which included the provision of safe passage and to ensure that I as a Bidjara woman would respect the protocols and lore of the land when undertaking research on country. I acknowledge the strength and culture of women's stories that have contributed to the development of this thesis. I could not have accomplished this study without such strong, resilient Aboriginal women who have guided the process and who were the identifiers of what is empowering for the women within their community.

I would like to extend a special thank you to all the courageous women from Hope Vale and Cherbourg for having foresight and the understanding of the importance of the serious issue of Foetal Alcohol Spectrum Disorder (FASD) and how it may impact on their lives. It has been a privilege to know each and every one of the women and to hear such richness in their stories. I pay tribute and honour an elder who before her passing always said to me "never forget the little children". This statement has always been with me and has helped to guide and direct my research journey which in turn has enriched my life as an Aboriginal person.

I will continue my acknowledgement to two very different Aboriginal communities, Hope Vale and Cherbourg. I acknowledge that there are words that may have been repeated to describe the welcome received from the participating communities.

Hope Vale

I would like to acknowledge and pay respect to the women who shared their cultural knowledge, traditions and stories providing a deep insight into a culture which is amazingly diverse. I recognise and extend an acknowledgement to all traditional owners of the Guugu Yimithirr Warra Nation and to the thirteen (13) Clan Groups that make up the township of Hope Vale (Thuppi). It is also important that I acknowledge the survivors of the forced removals of Aboriginal people from other parts of Australia to Hope Vale. Guugu Yimithirr is the main language spoken along with other related

languages as well as English. Hope Vale is situated in Far North-Eastern Queensland, located in a valley surrounded by tropical native bushland, mountain ranges, pristine coastal areas with diverse flora and fauna.

I pay my respect to the Aboriginal people both past and present who have and still continue to identify strongly with their ancestral lands along with their language, stories, songs, dances and histories associated to country. I would like to acknowledge and pay respect to the women who shared their cultural knowledge, traditions and stories which provided a deep insight into amazing diverse cultures. The welcome I received from the women made my learning journey a wonderful experience which also allowed a feeling of belonging to family. The women showed such resilience through the diversity they have faced with such strength, which is evident in their strong identity and their connection to country.

Cherbourg

The original name for Cherbourg was 'Burrumbeer'.

A Culture that was suppressed forcibly in a tiny community less than one century ago has proven, some fires never go out.

Cherbourg is located in the South Burnett region of South East Queensland near the township of Murgon and is situated on the old campsites and fresh water springs used by the Aboriginal people of the area. I acknowledge Cherbourg as the traditional land of the Wakka Wakka people, the traditional owners and custodians of their area which approaches the border of the Gubbi Gubbi people to the east, and home to the many traditional people who were removed from all areas of the State of Queensland and New South Wales.

The welcome received from the woman was with such grace and curiosity making my learning journey a wonderful experience and allowed for a feeling of belonging to family. My experience was truly incredible, amazing, as I had feelings of such peace, which are the feelings I have when I think of my connection to my country. The woman showed such resilience through the diversity they have faced with such strength, which is evident in their strong identity and their connection to country.

"We acknowledge the sovereignty and ownership of traditional custodial owners of all the first nations on whose land we live and work and we acknowledge both the past and present first peoples, their elders, languages, customs, culture and connection to this grand and wonderful country"

Support Team

I make special mention to my research team which consists of amazing and courageous individuals. Throughout my journey I have been very fortunate to have highly skilled PhD supervision provided by Professor Wendy Hoy (Professor of Medicine, Royal Brisbane Clinical Unit, The University of Queensland) and Professor Paul Coldtz (Head of School, School of Clinical Medicine, Faculty of Medicine, The University of Queensland). Both are outstanding clinicians and researchers in their specialised fields, showing dedication and commitment to scientific excellence.

Both Professor Hoy and Professor Coldtz present an ability to influence policy and practice, along with their effectiveness in directing the global and national agenda in their respective areas of expertise. Such professionalism has provided me with a strong example in leadership and an educative environment to learn from. Professor Hoy and Professor Coldtz have left very clear footprints that have guided the direction of my research journey.

My Associate Supervisor is Dr Leanne Coombe (Academic Lead Curriculum Design & Integration, Faculty of Medicine, The University of Queensland) who in the short time that she has been part of my team has shown such passion and dedication for her work. Her commitment, along with the deep intuition with which she operates, has shown me that research of the highest calibre can be implemented with great compassion. All members of my team have given me encouragement, support, and respect to continue on my journey to complete this very important research topic.

Professor Elizabeth Elliott, AM, Professor of Paediatrics and Child Health, NHMRC Practitioner and a Fellow Paediatrics and Child Health, Children's Hospital, Westmead has for the past sixteen years, provided encouragement, support and inspiration regarding my interests in raising the awareness of Foetal Alcohol Spectrum Disorders to the Aboriginal and Torres Strait Islander communities throughout Australia. A very

special thank you to Dr Cheryl Swanson who has given me valuable advice and direction relating to the quantitative chapters. Many thanks to Sue Mott, Anne Cameron, along with staff from Centre for Chronic Disease. I cannot thank you enough for your valuable support in sifting through the maze of the workings of the university.

I cannot forget my community supervisors, mentors and my cultural advisors from the different Queensland Aboriginal communities. Christine Stewart (Goreng Goreng, South East Queensland), Audrey Deemall (Thiithaar-warra, binithi, Eastern Cape York Peninsular) along with Dr Janet Hammill (Gomeroi, Far West NSW) and Dr Karen Thurecht having strong connections to the Gamilaroi Nation West NSW) all being my academic mentors and friends. These strong women from different walks of life have travelled with me throughout the duration of this research project which seemed to last forever and beyond, all were there to offer support and to bear witness to the telling, sharing, laughter and tears relating to the whole process of an Aboriginal woman's research journey.

A tremendous debt of gratitude is owed to members of the Aboriginal communities who so generously participated in intense community-based consultations throughout my FASD journey. It is the strength within the individuals that have allowed for the richness of their stories to be included with honour and respect. I would like to acknowledge many people in the community who were involved in the project. I am grateful for being given the opportunity, trust and freedom to undertake this very important work. More importantly, I would like to make a special thank you to all the women of the community who participated and so willingly shared their experiences and knowledge. Their support, warmth and friendship extended to me during my time as a visitor to their community is something that I will always respect and value. The various Community Health Services, Cherbourg Hospital, members of the Health Action Groups, were always there with valued support, guidance and for capably mentoring and facilitating me in the field.

I thank my family, especially my four daughters for their patience and persistence for keeping me going when I was forever tired, and my beautiful grandchildren, all sixteen of them, and two very precious diamonds, Ellah-Rose my great grand-daughter and Jarrah my great grandson, who have come to rest within my heart, and who inspire my mind and kindle my spirit, along with my extended family and friends. And how

could I forget Grandpa, who in the early years of my research drove me to near insanity with “you have to publish, publish, publish” - in hindsight I wished that I have taken his advice.

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Keywords

Foetal, Alcohol, FASD, Aboriginal, Maternal, Health, Risk, Trauma, Women, Culture

Australian and New Zealand Standard Research Classifications (ANZSRC)

ANZSRC code: 111712, Public Health and Health Services 20%

ANZSRC code: 1114, Epidemiology 60%

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Fields of Research (FoR) Classification

FoR: 111701, Aboriginal and Torres Strait Islander 50%

FoR: 111799, Public Health 25%

FoR: 111401, Foetal Developments and Medicine 25%

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List of Abbreviations used in the thesis

ABS	Australian Bureau of Statistics
CI	Confidence Interval
CJG	Community Justice Group
C&K	Crèche and Kindergarten
CNS	Central Nervous System
COTS	Children of Toxicity Syndrome
DOGIT	Deed of Grant in Trust
DoHA	Australian Government Department of Health and Ageing
FWNSW	Far Western New South Wales, Australia
FAE	Foetal Alcohol Effects
FAS	Foetal Alcohol Syndrome
FASD	Foetal Alcohol Spectrum Disorder
HACC	Home and Community Care
IKC	Indigenous Knowledge Centre
IPHC	Indigenous Primary Health Care
IQ	Intelligence Quotient
LGA	Local Government Areas
ND/AE	Neurobehavioral Disorder/Alcohol Exposed
NHMRC	National Health and Medical Research Council (Australia)
NSW	New South Wales

OR	Odds Ratio
PAE	Prenatal alcohol exposure
PCYC	Police Citizens Youth Club
PR	Prevalence ratio
QLD	Queensland
QRAM	Queensland Remote Aboriginal Media
RR	Risk ratio
SD	Standard Deviation
SE/AE	Static Encephalopathy/Alcohol Exposed

PART A: INTRODUCTION

1. Why docta not tell us; we weren't told?

1.1. Introduction

The origins of this research agenda and the reason for my involvement cannot be explained through coincidence or academia alone. Its development was motivated by my personal identity and my experiences as an Aboriginal woman along with the stories, the encounters, the debates, and the myths about Aboriginal peoples' drinking histories, their culture and their identity is what I wanted to explore and expose, especially in relation to women who are Aboriginal, who in many ways are considered racially and culturally different: *'the other'* within the Australian society.

It is the *'personal'* that has led to my questioning the value of the *'professional'* in my role as a researcher working in Indigenous Health. The exploration of being a fringe dweller is largely the well-defined margin between these two worlds that has spurred my desire to explore the meanings of Aboriginal uniqueness, societal customs and to recognize the impact of alcohol on the lives of Aboriginal people.

In defence of my reasoning I feel duty-bound to share my knowledge and to relay my own story as an Aboriginal mother, grandmother, great grandmother and elder of individuals who have been unintentionally exposed to alcohol during pregnancy. This is important as it speaks to how my own identity has influenced my research agenda before I seek to justify it within an academic context. Telling my own story of identity for me seems appropriate, it fits, it is the beginning of my learning and reflection upon my Aboriginality and cannot be separated out from the academic arguments of identity that I position myself within. It is often common practice within Aboriginal communities to disclose to each other where one comes from in terms of family, community, and country in order to find a common thread or bond and to provide some clues as to where one fits in the larger scheme.

In living my cultural responsibility to all women I have discovered an understanding of the links between alcohol and pregnancy. I have been through a series of academic awakenings as well as accumulating personal insights. As an Aboriginal woman and

student in a vast educational institution, I have had difficulty in separating the academic discovery from the personal.

As a result of my journey to identify the outcomes of prenatal alcohol exposure (PAE) and early life trauma in Indigenous children who live in Aboriginal communities in Queensland, I decided to compile a doctoral thesis from the experience throughout my personal, professional and academic life in the area of alcohol and pregnancy in conjunction with early life trauma.

1.2. Why Foetal Alcohol Syndrome (FAS)?

Twenty years ago in Queensland I discovered that engaging in discussions with medical professionals about Foetal Alcohol Spectrum Disorder (FASD) was very difficult. It appeared to be an area that was not clearly understood and General Practitioners' did not feel there was a need to speak freely to women of child bearing age about the dangers of drinking alcohol during pregnancy or to explain the potential impact of such behaviours on their unborn child.

Sadly, we now have two more generations of children who have been unintentionally exposed to alcohol in-utero and may have a diagnosis of FASD. After twenty years of lobbying, advocating and educating anyone who would listen about the dangers of drinking alcohol during pregnancy, I now find the situation in Australia has scarcely changed, particularly for Aboriginal women, as drinking during pregnancy continues, patterns of drinking have led to an increase in binge drinking episodes, and females who are drinking are younger and consuming more alcohol.

1.3. Why Weren't We Told?

There are issues that relate to women not knowing about the impact of drinking alcohol and the outcome of such behaviour on their unborn babies. A common response from women in my experience has been, *"why weren't we told?* The widespread use of alcohol and continued drug use among young women have raised community concerns that the long term effects of drinking alcohol and using drugs may have a devastating effect on the unborn foetus.

1.4. What can I do?

I wanted to develop a picture to identify how children who have been exposed to alcohol in utero develop and grow, by identifying variables that influence development outcomes and considering confounders such as tobacco, nutrition, drug and alcohol misuse by women and their partners. It was also important to establish insights into patterns of drinking behaviour on the reasons why Aboriginal women drink and the ways that alcohol use forms part of their everyday lives. My aim has been, over the past twenty years, to bring together research across various disciplines, to incorporate the voices of women themselves, and to provide a coordinated explication of the harmful effects of maternal alcohol and of the reasons why women drink. This information needs to be delivered back to health professionals and to women to consider ways that they can own, each from their own perspectives. This is what I can do.

As this thesis has been a long journey in the making, the references used throughout the chapters correlate to the period in which the research was undertaken.

1.5. The onset of my enquiry

At the commencement of my enquiry the primary objective was to identify the links between alcohol and pregnancy through the personal journey and stories of Aboriginal women. In 1997 I commenced an investigation about FAS and Foetal Alcohol Effects (FAE) in a remote Aboriginal community and in an urban city. This investigation explored the responses from Aboriginal youth aged 14 – 25 years, along with women's perceptions and experiences of maternal alcohol consumption and the effects on the child. The outcome of this study was the theory that the practise of consuming alcohol within Aboriginal communities can best be understood in terms of a life-cycle model of drinking behaviours. However, the models that are available had all been developed in Western psychological traditions and are inappropriate in many ways to the life pathways of Aboriginal people living in Aboriginal community settings.

The life stages experienced by people living in a rural Aboriginal community were investigated in light of the Western psychological models and the models were subsequently adapted to establish an appropriate life-cycle framework to assist in understanding drinking patterns and behaviours in Aboriginal communities. The life-

cycle framework is useful as it draws in all the various interconnecting factors and interacting complexities that feed into this cycle throughout one's life and over time, feeding into the environment, and feeding from the environment. This cycle is reproduced over successive generations, resulting in adults who systematically care for others, but take little care of themselves (Hayes, 1997).

There are continuing issues that relate to women not knowing about the impact of drinking alcohol on their unborn babies (Peadon et al., 2011). A common response has been *"why weren't we told"* (Aboriginal community member, personal communication, 1998). In 1998-1999, I carried out my first quantitative research project, a retrospective study examining antenatal records, and evaluating to what extent the records contained information relating to alcohol, tobacco, marijuana, and other substances used during pregnancy. I then designed a revised history chart to effectively gather information relating to alcohol, tobacco, marijuana, and the use of other substances during pregnancy and then evaluated the effectiveness of the new history chart in recording details of at-risk characteristics during pregnancy relating to alcohol, tobacco, marijuana, and other substance use (National Health & Medical Health Research Council, 2009).

As a result of discussions held with women and health workers in Cherbourg, a number of questions emerged concerning the assumption of obstetric risk. Although heightened risk is assumed, it is unknown what particular risk factors the women in the community actually have or the specific outcomes of their deliveries. It was decided that an empirical study was the most appropriate method by which to establish actual risk categories for women. The aim of the study was to measure the level of obstetric risk for women who had been transferred from Cherbourg to Kingaroy for the delivery of their babies over the past five years and to describe the details of the delivery and the outcomes for mother and child (Aboriginal community member, personal communication, 1998).

My passion to gain an in-depth understanding of maternal drinking gave way for the direction to track a pathway to undertake detailed research examining the effects of drinking alcohol during pregnancy on indicators of physical and psychological health in a newborn baby and in children aged five years. I decided to describe the drinking habits of the pregnant woman and to analyse the association between alcohol use

during pregnancy, and the health outcomes in the newborn such as birth weight, apgar scores, prematurity on external and internal psychological behaviours of the child at five years of age (Hayes, 2001a).

1.6. This Thesis

This thesis has been structured in three parts: the first chapters introduce the context for the research, and the second provide background on the topics contained in this thesis.

Chapter 3	provides a background on the communities of Hope Vale and Cherbourg in which the studies were conducted;
Chapter 4	outlines the methods used in the studies undertaken;
Chapter 5	explores the impact of colonization on the health and wellbeing of Aboriginal women;
Chapter 6	details the impacts of alcohol in pregnancy on mother and child; and
Chapter 7	investigates the models of Aboriginal alcohol use.

The third part of this thesis follows the separate investigations that were carried out, each with their own objectives as follows:

Chapter 8	explores perceptions of health and the relativity for the reasons why young women drink alcohol during pregnancy.
Chapter 9	analyses risks of maternal alcohol consumption on the new born infant and the 5 year old child through analysis of data supplied by the Mater Hospital and the University of Queensland;
Chapter 10	evaluates a surveillance system with the collaboration of the District Rural Health Service in Cherbourg; and
Chapters 11 and 12	investigates obstetric risk in mothers who were removed from Cherbourg to deliver their babies in a rural hospital Kingaroy

	General Hospital, in partnership with the Cherbourg Health Action Group, Cherbourg Community Health Service; and
Chapter 13	records stories of maternal alcohol use and Aboriginal women's experiences.

However, I begin in the next chapter with the telling of my story. My story brings coherence to the data, context to the research and deep meaning to the journey. I would like to share some of the threads that have helped shape the tapestry of my life's journey.

2. Jarrabin: An Aboriginal woman's experience - living in three worlds

My own story brings coherence to the data, context to the research and deep meaning to the journey. I would like to share some of the threads that have helped shape the tapestry of my life's journey

2.1. Introduction

In 1971 Carole King wrote and sang the Tapestry (King, 1971), depicting how every experience becomes a thread that makes up the colourful tapestry of our lives. This chapter is written with storylines that are delightful, and tales that are sorrowful and angry. It is about the many facets of being an Aboriginal woman in Australia. My tapestry is woven thickly with strong family threads with an undeniable connection to Central Western Queensland, my birth place on the Tropic of Capricorn. I am a Bidjera woman who comes from a family history of artists, educators, story-tellers, authors, healers and law people. I have ancestral links to the Innangi people from Western Queensland and a sprinkling from a promiscuous Irish male who came from Melbourne, Victoria. He was told at a young age to "go forth into the wilderness and become a man" (Aboriginal elder, personal communication, 1968). His place of arrival for breaking new ground was to be Central Western Queensland. Through his bloodline this person became my unintended maternal grandfather.

2.2. My backyard

I grew up with my feet firmly connected to the sand hills and red dirt of the west along with the smell of Gidgee and the Brigalow scrub. Although dry and harsh at times my playground was a fertile arena, which is set into my consciousness, which has allowed for an enquiring and inquisitive mind. This curious mind upheld my strong grasp of bush skills and knowledge. I grew up with a love for the Australian bush and was taught how to survive and how belong to the bush; how to respect the bush; how to recognize the trees which had dark brown gum oozing out from under their bark which was to be the 'local bush toffee', straight from the tree; how to recognize the smells, the sounds, the rustlings in the long grass and dead leaf matter and how to recognise the animal tracks. Although I was not very interested in animal tracks at such an early stage in

life, these lifelong lessons were nonetheless provided by my grandmother, grandfather, father and aunties.

As a young person I always liked my own personal skin, my own being, my privacy to be a loner to enjoy the peaceful serene quietness of the bush especially near the creeks, dams or anything that had water in it, attracting me to the simplicity and straightforwardness of the occupied space in the bush. During visits to the lakes and billabongs, closest to where I lived as a child, one could notice the abundance of birdlife, black swans, ducks, brolgas and jabirus all trying to find a space on the edge of whatever water they could find. Lazy kangaroos and emus lay nestled in the distance resting in the sparse shade from the unrelenting sun of the West. This was my backyard.

My paternal family were stockmen and stockwomen. My grandfather and father were drovers and both paternal and maternal grandmothers did not shy away from mustering and droving, for all of which I have an abiding respect. Both my grandmothers were strong in the saddle. My maternal grandmother worked and rode horses on Listowel Downs, a pastoralist station situated on the Blackwood Creek, 90klm from Blackall in Western Queensland (Unknown, 1944).

Figure 1: Lorian Hayes nee (Fraser). My first droving experience 1951

My fondest memory as a child was being at my Aunt's house, sitting on the edge of an open veranda being very brave not to fall over the edge. I would swing my legs back and forth with such vigour, waiting and looking far into the distance, as far as my eyes

could see, looking for a sign that my grandfather and others were coming home. I was looking for a cloud of dust made by men riding their horses on dry and dusty ground; the dust would roll in from the faraway northern horizon. Quietly sitting and waiting for my family to arrive, I had time to submerge myself with respect and joy for what this land in the Central West has to offer; such as incredible sunsets with the most glorious colours of deep reds, purple, lilac and all shades of yellows and oranges. What a truly amazing experience. I can remember my grandmother walking past where I was sitting and speaking whilst her tobacco pipe hung from the side of her mouth. *"See that girlie, when that sky is really red it is going to be cold tonight"* (Nanamullii - Paternal grandmother, personal communication, 1960). As a child I did not understand how my grandmother could have such knowledge. I'm still not sure how she understood this back in the early 60's.

My early memories in life were of gratitude and appreciation for what I have. I will always feel compassion and admiration for my mother, grandmothers and aunties, and honour them for their survival instincts and their sheer determination. And the way that they pushed me to conform, to get an education. This idea was long-established by my paternal grandmother who always said: *"you have to go to school 'girlie' and get educated so that you can sit at the table and talk with those white fellas"* (Nanamullii - Paternal grandmother, personal communication, 1960). Where am I today? I am sitting at the table deep in discussion with *'white fellas'*, thanks to the strong women who were role models in my life.

2.3. Living in different worlds

I have lived through a time of enormous cultural change in Australia. I have vivid and often poignant recollections of my rural experiences as a child. My father finally gave up droving and was employed by Queensland Rail, firstly as a fettler (labourer) and then a ganger (boss), repairing railway tracks. This urban childhood has continued to resonate during my survival through this era.

It became a practice throughout the years that Queensland Rail would send my parents to work where ever it was needed. We moved to many different country towns throughout Queensland. I began my education with correspondence through the School of the Air, and then attended four primary schools and three secondary

schools. I didn't have much time to make long lasting friendships, as we were always on the move.

During my years at both primary and secondary school I came to realise that I was not only the sole Aboriginal girl in the class but the only one in the school. I became torn between different worlds, during those years, being an Aboriginal at home and with my family and yet somehow standing back from my peers throughout school. I knew that I was somehow different to them. As shy as I was I managed to somehow survive my schooling years.

After departing from secondary school, I applied to enter into Nurse's training school at the Barcaldine Base Hospital in Central Western Queensland. I began my nursing career in 1967. During the following years I became disillusioned with the orthodox approach to health and healing. Again, my grandmother's wisdom and remembering her words of encouragement to get an education were with me when I discovered a pathway that lead me on a journey to explore other options of healing. These came in many forms: Acupuncture and Traditional Chinese Medicine was one form that I embraced with passion as it gave me the opportunity to enter a world that I did not realise existed. I came to a period in my life where I chose to unfold my wings and embrace the world of academia.

2.4. My journey through the maze of academia

I have continued to honour the memory of my grandmothers and the expectation that an education is so very important for Aboriginal people.

I always wanted to go to university, so when the opportunity arose in 1977, I decided to undertake a course on Social Welfare and Community Recreation which gave me the qualifications to support students enrolled in teachers, training at the Kelvin Grove Teachers College in Brisbane, which is now Queensland University of Technology. As a counsellor I became interested in social justice and became involved in supporting women and children who were victims of domestic violence.

Many years passed, and a new course was developed to encourage Aboriginal and Torres Strait Islander people to gain entry into the University of Queensland. This new

course was the Bachelor of Applied Health Science that specialised in Indigenous Primary Health Care (IPHC).

Throughout my undergraduate years I was confronted with the reality of being an Aboriginal student in such a vast academic institution, I realised at the time that this was going to be the beginning of a challenging journey. There were many expectations placed upon myself and my peers, to be perceived as of the same standard as the wider university student population. As an Aboriginal student, I felt that I had to be "better than" the others so that I would be perceived to be "equal to" other non-Aboriginal students. I strove to achieve distinctions and believed these were only the equivalent of a fellow non-Indigenous' student who received a pass.

2.5. My research career

During my third year with the Bachelor of Applied Health Science (IPHC) I embarked on my career in research with my first research project. I chose a topic that was close to my heart: maternal alcohol consumption during pregnancy and the developmental outcome for the new born infant being born with FASD. Initially my aim during this research project was to document and analyse the awareness of FAS and FAE among young Aboriginal women and men aged between fourteen and twenty-five years. However, the age group became extended to incorporate the various age ranges of interested community members in Hope Vale. The study explored perceptions of health and the relativity of the reasons why young women drink alcohol during pregnancy. My observations not only included adults and adolescents, but the children also formed an important part of the study group in the remote Cape York community of Hope Vale in 1997 (Hayes, 1997).

During my honours year I was invited to undertake research in Cherbourg, I realised that the people in my study had little or no knowledge of the risk of alcohol consumption during pregnancy. I began with an ethnographic approach, using participant observations, yarning circles and interviews. It became evident that women's priceless stories were incredibly rich, and it was important that the women's voices should not be lost.

As a postgraduate student interviewing a group of women who were known to me and had willingly agreed to be interviewed, I found little help in the standard methodological

approaches and the guidebooks that would assist me in accepting and representing the issues that I would be confronted with, as an Aboriginal woman carrying out research with other Aboriginal women. I believed that I worked across three levels; the first, being the 'insider' as an Aboriginal woman and as a mother; and at another level being an 'outsider' as a woman who did not live in the study communities, as someone from a different tribe and language group, and as an elder; and thirdly as a postgraduate student doing research.

As a researcher, I discovered that qualitative research could be really exciting: understanding the world views from the perspective of others is an important lesson. During the process of this particular study I felt that it was very important to show respect and to honour the people's way of doing and believing, and to understand the young people and their interpretation of the dangers of maternal alcohol consumption during pregnancy. It became apparent there was also a need to provide education and support and to provide capacity building for the individuals in the community.

The approach that I selected led to raising awareness of FAS, (the medical diagnosis that sits under the umbrella term of FASD or FASD) in the community. The use of this educative approach not only taught participants about the dangers of FASD but also left them feeling empowered and enriched with new knowledge that they could share within their communities.

At the end of my work it was made clear to me by the academic establishment that my dedicated commitment to the voice of the people did not hold the same credibility in academic terms as the measurable data collected through quantitative methods. After discussions were held with supervisors and peers, I considered that quantitative methods were considered to hold more strength and credibility than qualitative approaches. To move forward with my understanding of the different methods used for research, I decided to learn and understand the clear difference between the various options that would give strength to the data collected thought my research journey. It was essential that I have the strongest voice possible to advocate on behalf of my people.

After receiving a prestigious scholarship, I went on to study a Master of Applied Epidemiology at the Australian National University, which gave me the confidence,

skills and empowerment to build capacity in the communities, participate in debates and discussions, and to 'sit at the table with the white fellas' as my grandmother advised all those many years ago.

2.6. Where to – Canberra or the Community?

After all the study and research, I needed to leave Canberra and return to the community. An Aboriginal Elder said quietly to me *'they go off and get their degrees and they forget about the people in the community especially when they do the research in the communities'* (Aboriginal elder, personal communication, 1992).

Through my many years of working in the communities, living alongside community members, assisting in building capacity so that Aboriginal people could have an in-depth understanding of the issues that I had discovered, I became convinced that in fact, the only way we can truly understand the complex interplay of alcohol and its biological effects on the developing embryo and foetus is through listening to the people's stories.

Quantitative measurements are useful for confirming specific links between variables, however only the depth of information gained through observation and listening can begin to unravel the complex ways in which these variables are woven into the tapestry of people's lives. I have enormous respect for the disciplines of epidemiology and statistics, however I have come full circle in my own research career, and find myself back where I started, and listening to the rich stories of the people I work with. The difference between then and the present is knowing that I now have the confidence to know the value of their stories in the academic sense as well as within my own heart.

Rolling Thunder, a great Cherokee Chief stated: "You can't just sit down and talk about the truth. It doesn't work that way, you have to live it and be part of it and you might get to know it."[2]

[2] https://www.tapatalk.com/groups/cheyennegathering/rolling-thunder-cherokee-quotes-t515.html December 11th, 2008, 7:58 pm #7

2.7. Conclusion

With the desire to continue my education into a long and healthy career, alongside being a housewife and a mother, I have come to realise that these roles were, and still are, very difficult to display as an Aboriginal woman. I have always been the person who stood in the background listening to discussions of others, analysing every word that was spoken; not being the one to engage in discussion. The relaxing non-committed behaviour of being in the background of my past has today given me a strong sense of personal completeness and strength to now enjoy the engagement of discussion.

When the opportunity arose to make a difference, especially as it related to the subject which is closest to my heart, I grasped it with both hands devoting two decades of my life to a journey that has opened many different worlds. I still believe that in the long-term education will at least partially equip us for the future. As my grandparents said all those years ago, at least “it will allow you to sit at the table”. Through this journey I have come to understand myself and feel easier about who I am as an Aboriginal woman, an educator, and a researcher.

3. Where I undertook the research

From the Guuguy Yimidhirr Warra nation to the Wakka Wakka nation: Where the creation of a research journey began by an Aboriginal woman from the Bidjara nation

3.1. Introduction

Firstly, I acknowledge the two traditional countries within Queensland, Australia for their warm 'Welcome to Country' which included the provision of safe passage and to ensure that I, as a Bidjara woman, would respect the protocols and lore of the land when undertaking research on country. I acknowledge the strength and culture of women's stories that have contributed to the development of this thesis. The welcome I received from the women made my learning journey a wonderful experience which also allowed a feeling of belonging to family. The women showed such resilience through the diversity they have faced with such strength, which is evident in their strong identity and their connection to country.

3.2. Hope Vale (Warra Nation)

The Hope Vale township is situated on the Cape Bedford Peninsula 46km north west of Cooktown in Far North Queensland and is located in a valley surrounded by tropical native bushland, mountain ranges, pristine coastal areas and diverse flora and fauna. Hope Vale is located on the traditional country of the Guuguy Yimidhirr Warra nation. The language commonly spoken is Guugu Yimithirr. The Guugu Yimithirr people, like all Aboriginals in Australia, have been here for approximately 100,000 years (Ganter, 2016).

3.2.1. The History of Hope Vale

In 1881, the Queensland Government gazetted land at Cape Bedford on Cape York Peninsula as an Aboriginal reserve. During 1886, a Lutheran missionary Johann Flierl successfully negotiated with the Queensland Government to establish a mission at Cape Bedford known as Hope Valley. Flierl relocated the settlement to a bay north of Cape Bedford, which he named Elim. On Flierl's departure in 1887, Lutheran

missionary George Schwartz became his replacement and remained at the mission for more than 50 years (Ganter, 2016).

3.2.1.1. World War II

In 1942, during World War II the military interned the German Lutheran missionaries, and the population from Elim were evacuated to southern communities such as Woorabinda, an Aboriginal community in Central Queensland, located inland about two hours' drive west of the coastal city of Rockhampton, Australia (Queensland Government, 2019b).

As a result of environmental changes, extreme weather conditions and a poor water supply, more than 28 deaths were recorded from disease after the evacuation. Over the next 8 years, more than a quarter of the population died. At the end of World War II, the people who were removed from Elim, were allowed to return to their community on Cape York Peninsula in Far North Queensland. Due to a lack of reliable water supply at Elim, George Schwartz moved the community to its current site about 20 kilometres inland. In September 1949, Hope Vale was re-established as a Lutheran Mission and all Guugu Yimithirr speaking people returned to present-day Hope Vale with the first families returning in 1950. George Schwartz was named Muni by the Aboriginal people at Hope Vale.

It is also important to acknowledge the survivors of the forced removals of Aboriginal people from other parts of Australia to Hope Vale. An example of this removal is the Inningai people from Western Queensland, who were forcible removed from their country and sent to Cape Bedford east of Hope Vale in 1912 (Hope Vale Elder, personal communication, 2019).

3.2.2. Background

Hope Vale has a population of approximately 1015 people, comprising of thirteen (13) groups that include the Thuppi, Nukgal, Binthi, Thitharr, Dharrpa, Ngayumbarr-Ngayumbarr, Dingaal, Ngurrumungu, Thaanil, Gamaay, Ngaatha and Burunga Clans. A representative body for the 13 clan groups is known as the Hope Vale Congress Aboriginal Corporation. The Corporation is comprised of members from each clan group who decide on matters relating to land management for their respective clan group areas.

In addition to the mentioned clans, the community is made up of the Guugu Yimidhirr speaking peoples, the Yiidhuwarra (traditional owners of Barrow Point, Flinders Island, and the South Annan), the Bagaarrmugu, Muunthiwarra, Juunjuwaara and Muli people plus the Gungarde and Bulgoon people from the south, the Kings Plain's Thukuun Warra people and the Sunset Yulanji people from the Maytown area. The most common Indigenous language spoken in Hope Vale is Guugu Yimithirr and other related languages, as well English.

3.2.3. A Deed of Grant in Trust Community

Aboriginal Deed of Grant in Trust (DOGIT) land is State land granted by the Governor-in-Council under the Land Act of 1962, for the benefit of Aboriginal inhabitants or for Aboriginal purposes. A DOGIT community, is the name that was established by Queensland Government to administer former reserves and missions to have a system of community-level land trust. In 1984, the Community Services (Torres Strait) Act and the Community Services (Aborigines) Act by the Queensland Government was then created to own and administer former communities under the DOGIT (Department of Natural Resources and Mines, 2015). Essentially it means that the Crown reserves the rights to the resources that may lie within the property boundary. The trusts are governed by local representatives who have elections every three years and are known as Incorporated Aboriginal Councils.

Between 1984 and 1986, fifteen Aboriginal DOGITs were granted in Queensland. In 1986 Hope Vale received a DOGIT and formed the Hope Vale Aboriginal Council. These councils have the power to pass by-laws, maintain housing and infrastructure, and approve permits for camping and fishing.

3.2.4. Hope Vale Aboriginal Shire Council

In 2004, the Community Council became a Local Shire under the Local Government Act. The administration of Hope Vale was transferred from the State Government to the Community Council. Since then the community has witnessed continued improvements in housing and redevelopment of existing infrastructure. This includes a swimming pool, sporting complex and several thriving industries, especially the dairy and vegetable/herb farm which supplies stores in other towns. A reliable source of electricity supply is available to the community, with a safe and reliable water supply and an efficient sewerage system in place.

Hope Vale has a range of community services and is also a pilot site for the Cape York Welfare Reform project. Services provided in Hope Vale include Disability Services, the Well Being Centre, a Swimming Pool and Splash Park, and a Sporting complex all of which are used by all community and visitors in Hope Vale, as detailed below (Hope Vale Aboriginal Shire Council, 2019)

3.2.4.1. Health

Queensland Health provides a twenty-four hour primary health care clinic offering a range of services including clinic facilities and accommodation for visiting services. The clinic offers on-call after hours Accident and Emergency, Child and Adolescent Health, Women's Health, Mental Health, Sexual Health, Chronic Disease, Environmental Health and Disease Control, Diabetes and Nutritional Health, Alcohol and Substance Use, and Aged Care. A range of visiting services and specialist from Cairns and Weipa, also complement the essential services. Financial assistance through the Patient Travel Subsidy Scheme (PTSS) is eligible to patients who need to travel to other hospitals for procedures and tests that are not available locally. A purpose-built dental suite provides comprehensive dental care to the local community. Telehealth services are available for linking with other facilities via video-conference for patients.

Apunipima Cape York Health Council's Chronic Disease Team from Cooktown provide specialist outreach programs including a Women's Health Service, Sexual Health Service, and the Cape York Mental Health and Alcohol and Drugs Health Service. There is a Wellbeing Centre in Hope Vale that provides a range of social and emotional wellbeing services. This service is managed by the Royal Flying Doctor Service (Medical Doctor from Apunipima Cape York Health Council, personal communication, 2019)

3.2.4.2. Hope Vale Aged Care Facility

The residential aged care facility offers a twenty-bed home environment with access to a registered nurse providing twenty-four hour care, seven days per week. The primary focus of the nursing home is to provide palliative care which is recognised as an important service within the community. Couples accommodation is provided as well with a secure garden along with the provision of pets on the premises. The

recognition of Aboriginal and Torres Strait Islander culture is paramount within the Aged Care Facility (Hope Vale Aboriginal Shire Council, 2019).

3.2.4.3. Crèche and Kindergarten (C&K) Child Care Centre

The Child Care Centre in Hope Vale provides a high priority C&K service where parents and children feel happy, healthy and safe. This environment is achieved through the use of positive behaviour guidance strategies, the employment of high-quality educators, the provision of natural play spaces and by maintaining high standards and hygiene (The Creche and Kindergarten Association Limited, 2018).

The C&K *Building Waterfalls* program is Australia's first collaborative birth to school age curriculum framework which is delivered throughout C&K's Child Care Centres and is universally acclaimed as inspiring and thought provoking, taking early childhood education to a new level.

3.2.4.4. Home and Community Care (HACC)

The HACC program provides basic support to the frail and elderly and to people with a disability who want to continue to live in their community. These services provide eligible people with help at home, support in getting out into the community, and a break for carers (Hope Vale Aboriginal Shire Council, 2019).

3.2.4.5. Community Justice Group (CJG)

The role of the CJG is to ensure that clients of the service are given appropriate cultural support for court matters. The CJG also provides cultural reports to the courts at sentencing and bail applications, assistance to the courts in managing community-based offences, and networking to implement crime prevention initiatives. The CJG works to support the community's understanding of, and access to, the justice system by working in conjunction with Shire Council by-laws and victim support agencies.

3.2.4.6. Police Citizens Youth Club (PCYC)

The PCYC is Australia's pre-eminent youth organisation working with Police and community to empower young people to reach their potential (Hope Vale Aboriginal Shire Council, 2019).

3.2.4.7. Education

Hope Vale has a strong track record of success in education fields and teaching with the highest number of Indigenous registered teachers of any community in Cape York. Although some Indigenous registered teachers have retired or moved to other successful careers there are still a significant number of local Indigenous teachers on staff and leading the school community.

Hope Vale campus is a primary school encompassing prep to Year 6 and does not offer secondary education in the community. Students often travel south to attend boarding school or attend the secondary school in Cooktown (Hope Vale Aboriginal Shire Council, 2019).

3.2.4.8. Radio Station

Queensland Remote Aboriginal Media (QRAM) services have been tailor-made to the requirements of each individual station, including training, technical support, general administrative support, representation of the region to government and broadcasting industry bodies, assistance with licensing including renewals and secretarial support. QRAM Aboriginal Corporation was formed in 2006/2007, becoming fully operational in July 2007. Cape and Gulf communities can hear a modern, progressive and informative voice that they own and control with greater service provision especially during extreme weather conditions and events, such as cyclones (Hope Vale Aboriginal Shire Council, 2019).

3.2.4.9. Indigenous Knowledge Centre (IKC)

The purpose of the IKC is to document and record the local histories, stories and language within Hope Vale as part of their local collections. The IKC role is to coordinate and organise a range of programs and activities that support the documentation, maintenance and preservation of the different language groups within Hope Vale. Such activities may include recording language and conducting language workshops in the community.

Other services provided by the IKC are delivered at the discretion of the Council. These services may include public access to information technology, public programs,

family history research and the preservation of materials (Hope Vale Aboriginal Shire Council, 2019).

3.2.5. Alcohol Restrictions

Since 2003, the Queensland Government legalised restrictions to the type and quantity of alcohol that may be brought in to a number of Indigenous communities (Queensland Government, 2019a).

These restrictions vary for each of the different communities in Queensland. The law applies to all residents and visitors to the community. The aim of alcohol reforms is to reduce alcohol-related harm, especially to children, women and other vulnerable community members. This is being achieved through alcohol restrictions and improved services and partnerships between government and community, including support for positive community actions. Currently, Hope Vale community has a range of restrictions on the possession or carriage of alcohol in the community.

3.3. Cherbourg

The original name for Cherbourg was ‘Burrumbeer’.

A Culture that was suppressed forcibly in a tiny community less than one century ago has proven, some fires never go out.

3.3.1. Introduction

During my journey I discovered the need to explore the use of alcohol and other substance use during pregnancy within Cherbourg Aboriginal Community in South East Queensland. This chapter provides an outline of the community and its context.

3.3.2. The History of Cherbourg

In 1894 the Queensland government commissioned Archibald Meston (1851-1924), journalist, explorer and amateur anthropologist, to make recommendations for improving the condition of Queensland Aborigines. Meston recommended their segregation from the European population, protecting them from alcohol and opium and providing better medical attention and 'instruction in industrial habits'. His report resulted in the passage of the Aboriginals Protection and Restriction of the Sale of

Opium Act by the colonial legislature in 1897. As outlined in Chapter 4, throughout our history, there have been many policy eras that Aboriginal people have been subjected to, ranging from the British Invasion, Protection, Interrogation, Segregation and Assimilation. During the period of 1897, the Aboriginal Protection and Prevention of the Sale of Opium Act was passed by the Queensland Government (Parliament of Queensland, 1897), which made way for the creation of reserves, missions and allowed for the provision of forcibly removing Aboriginal people to these reserves. People were consequently contending with different country, different tribal boundaries, different meanings, no stories to relate back to country, and different culture from their new neighbours who were not known to them or possibly from other tribes with whom they were at war. This meant being dislocated from one's homeland and being forced to subsist under deplorable conditions.

3.3.2.1. Barambah Station

A Salvation Army officer at Nanango, William Thompson, secured 7000 acres from the Barambah pastoral station in 1901. On the 30th April (1901) land was designated at Barambah Station, about sixty miles from Gayndah, for an Aboriginal settlement. A few local Aboriginal people were soon joined by thirty-three people from Kilkivan and forty people who had been rounded up like cattle and walked from Woodford. The government run mission opened in 1903 (Cherbourg State School, 1998).

Its establishment predated the beginnings of Murgon township by three years. Thompson gathered local Aborigines onto the mission station and was superintendent until 1904. Conditions were rudimentary, worsened by drought and lack of finance. Control of Barambah passed to the state government in 1905.

Aboriginal people from forty different tribes were eventually settled at Barambah Mission and in 1931 the settlement was renamed Cherbourg. The community has a long history of disadvantage, as described in the *Dumping Ground* by Thom Blake (Blake, 2001). People from far and wide were 'dumped' in the community, forced to live together, and prohibited from speaking their own languages and undertaking cultural significant events that had a great impact on their lives. In the early days, the provision of accommodation, food, education, religion and health facilities were less than basic and traditional culture was not only ignored, but forbidden. This resulted in

annihilation of their cultural heritage and extinction of many of their languages and cultural practices. To communicate, people developed a common language from pigeon which has been called *Mission Talk*, *Cherbourg Talk* (Cherbourg State School, 1998). The people lived in makeshift shacks and for decades provided an abundant and cheap labour force for surrounding properties (Cherbourg Community Council, 1994).

In the twenty-year period, during 1905-1925, the community experienced 923 deaths with double the number of births. In 1919, 20% of the populations, 124 lives, were claimed by the Spanish Influenza. Evidence shows that inadequate food rations, one blanket per person and children living in dormitories constructed of bark and corrugated iron along with sleeping on the bare ground gave way to hard desperate living conditions in Cherbourg.

The population of Cherbourg grew from 500 during the 1920's and had reached 900 by 1930, although the people of Cherbourg were not counted in the census prior to 1967. The 1996 census identified 1100 people of Aboriginal and or Torres Strait Islander descent living in Cherbourg (Australian Bureau of Statistics, 2013). In the year 2000, the population estimate has increased to between 2000-3000 people. There are approximately 60-80 babies born each year to women in Cherbourg (information gathered from Cherbourg antenatal clinic, 2010).

Cherbourg became a DOGIT Community, which is the name that was established by Queensland to administer former reserves and missions to have a system of community-level land trust. The Community Services (Torres Strait) Act and Community Services (Aborigines) Act in 1984 by the Queensland Government was then created to own and administer former communities under the DOGIT. The trusts are governed by local representatives who have elections every three years and are known as Incorporated Aboriginal Councils. These councils have the power to pass by-laws, maintain housing and infrastructure, approve permits for camping and fishing. Today, Cherbourg is no longer a discrete DOGIT Aboriginal Community; it now is part of the Local Government Authority (LGA).

In 2004, Cherbourg performed its first 100 years Centenary Celebration, which turned out to be a huge success & a very well-organised event.

3.3.3. Background

Cherbourg community is situated on Bunya Highway in South East Queensland, 6km from the town of Murgon and 250 kilometres north-west of Brisbane and covers an area of 13,230 hectares, approximately 108 square kilometres (Wikipedia).

Cherbourg is within Wakka Wakka tribal boundaries and bordering onto homelands of the Gubbi Gubbi territory to the east. Cherbourg has many leading citizens, performing artists, writers and sports people who have achieved national and international acclaim.

3.3.3.1. Environment

Cherbourg is accessible to neighbouring towns by sealed roads and travel to Kingaroy by road takes approximately 45 minutes. There is a daily return bus service to Brisbane, with no local bus service to Cherbourg and the closest air strip is Wondai. Emergency evacuation of patients is either by road ambulance or by helicopter from Brisbane. A reliable telephone network is accessible with a mobile phone network being available with specific service providers.

3.3.3.2. Community services

The administration of Cherbourg was transferred from the State Government to the Community Council in 1986. Since then the community has witnessed continued improvements in housing and redevelopment of existing infrastructure. This includes a swimming pool, sporting complex and several thriving industries especially the dairy and vegetable/ herb farm which supplies stores in other towns. A reliable source of electricity supply is available to the community, with a safe and reliable water supply and an efficient sewerage system in place.

3.3.3.3. Community organisations

Cherbourg has a large range of community services. These include Barambah Regional Aboriginal Medical Service (BRAMS), a rural district hospital, a Qld Health community health service, Gundoo Day Care Centre, Beemar Yumba Children's Centre, Jundah Women's Shelter, Wunjuda Alcohol and Substance Abuse Rehabilitation Centre, Barambah Community Care Agency, Outreach program for

juveniles, Welfare Association, Rugby League Club, health rights action group, and a Community Justice Group. Cherbourg Council controlled facilities and services include Nyku Byun Aged Hostel, the Respite Centre and a driving school.

There is a pre-school and a primary school. Children are also transported to Murgon and Kingaroy to attend one of the primary schools of their choice, Murgon State Primary School, St Joseph's catholic primary school (Murgon) and St Mary's (Kingaroy) which is a co-ed catholic school offering classes from primary through to secondary, year twelve. Murgon has a State High School, and there is a TAFE college in Cherbourg which offers skills based development programs and apprenticeships.

3.3.3.4. Health Service

The Cherbourg Hospital (Rural District Health Service) provides inpatient and outpatient services along with a twenty-four hour emergency care. Medical care includes minor surgical procedures and antenatal and postnatal care. Patients are transferred to Kingaroy Hospital for serious conditions, specialist treatment, surgery and childbirth.

The local hospital is located centrally within the community. The facility has twenty-six beds, consulting rooms, basic x-ray facilities and an accident and emergency room which is also equipped for unplanned deliveries. A resident medical superintendent and director of the Rural Health Service, staff the hospital. (Sellars, S., personal communication, 2000).

3.3.3.5. Maternity Services

In 1994 the community witnessed the beginning of the Women's Health Program employing two midwives and one Aboriginal health worker. One midwife worked part time. Together they provide a holistic service that addresses all areas of women's health. The community midwives and the Aboriginal health worker also provide a model of care and share the antenatal care of clients with the medical superintendent at Kingaroy Hospital. Focus group discussions revealed that the medical model provided by the Cherbourg Hospital prior to the commencement of the Women's Health Program did not meet women's needs. This was reflected in their reluctance to present for care (Cherbourg women, personal communications, 2000).

The Women's Health Program currently works out of what is inaccurately referred to as the Birthing Hut because no births occur here. It is a small low-set building separate to the main building but situated in the grounds of the hospital. Consisting of two rooms and a small kitchenette, it is quite inadequate for its purpose, namely clinical consultations and education. The midwife and health worker provide antenatal care and support during labour, with a midwife being on call at all times. The uniqueness of one to one maternal education is provided in a variety of settings as identified by the clients.

The midwife and the medical superintendent at Kingaroy Hospital provide a shared care arrangement for pregnant women. Women from the community undergo routine ultrasounds. One routine antenatal visit to Kingaroy Hospital is recommended at thirty six weeks gestation. During their labour, women who do not have private transport and are in labour are taken by health staff, and the midwife to Kingaroy Hospital. This is a distance of 48 kilometres or forty –five minutes away by road. Transport is also arranged after confinement to return to the community. Postnatal care is provided by the Women's Health Program and the infant is referred to the Child Health Program, Community Health Services. It has been noted that women sometimes present late during their labour and this is thought to be a deliberate act so that they may to deliver in Cherbourg and avoid transportation to Kingaroy (Watcho L, personal communication, 2000).

3.3.4. The Cherbourg study

The following Chapter investigates the District Rural Health Service data collection on social health risk factors such as the use of alcohol, tobacco and other drugs during pregnancy. It is vital that information regarding the use of alcohol, tobacco and other drug use is collected with the intent that effective programs be introduced working towards reducing obstetric risk.

PART B: THEORETICAL CONSTRUCTS

4. Looking, Listening, Counting and Learning:

Reflection and Analysis using a Simple Research Process

4.1. Introduction

This thesis consists of several different techniques in data collection that represent the various research projects carried out by myself over the last eighteen years. The Children of the Grog Study is a multi-stage, mixed methods study, combining medical anthropology, ethnographic techniques, chronic disease perspectives, early life trauma and psychiatric epidemiology, and is aimed at exploring the links between psychological and physical ill-health among Aboriginal women in Cherbourg South East Queensland Australia. It has involved the use of both qualitative and quantitative methods, with approaches from both disciplines utilized to develop appropriate tools and understandings to explore the links between psychosocial stress, alcohol consumption during pregnancy and early life trauma.

4.2. Qualitative research

Qualitative research methods were used to test and confirm a model of alcohol use in Aboriginal communities. The model acknowledges that alcohol use is part of a common, pathological life-cycle, determined by historical, cultural and economic circumstances.

The use of qualitative research methods is affiliated with various academic fields such as cultural anthropology, sociology, and psychology; it also sits comfortably with the Indigenous framework for understanding through story. It is now being utilised is a number of applied professions, which include education, nursing and public health. Qualitative research methods provide for a holistic approach to gathering information to understanding the finer details of human behaviours. It allows people to tell their stories and it allows the researcher to hear the stories within the context of people's lives. The value of qualitative research methods lies in its ability to identify and examine the culture and behaviour of groups as well as that of the individuals, from

the point of view of those being studied (Patton, 2002). Qualitative research emphasises the understanding and recognition of a holistic approach to cultural backgrounds in which the research is conducted (Bryman, 1992).

Qualitative information is like a mountaintop view; it is panoramic and awe-inspiring, yet seductively attractive. The best qualitative information provides rich descriptions and well-founded rationale for explaining the underlying behavioural and environmental processes at work in local settings. It places persons and their families within this historical picture and shows in a realistic sense how they adapt to changing conditions both culturally (in the form of role changes, for example) and socially (i.e., alterations in the family development cycle).

The key to qualitative research, therefore, is to understand the context in which decisions, actions and events occur (Yoddumnern-Attig et al., 1993). A valuable indicator in actualising the role of culture is that all research data must be interpreted in its particular context. The context is made up of historical, economic, social, political, and geographical elements. This means that the culture of any group of people, at any particular point in time, is always influenced by a number of factors. It is therefore impossible to isolate pure cultural beliefs and behaviours from the social and economic world of the individual (Helman, 1994). In addition, Smith (2012) notes it is impossible to isolate the individual or the self from the contextual world of her or his positioning in time and place.

For example, people may behave in a distinct manner (such as living in overcrowded conditions; neglecting to see a doctor when they are ill) not because it is their culture to do so, and not because it is in their individual psychology to be irresponsible, but because they are economically disadvantaged, or financially unable to survive in any other way.

This approach (qualitative) has held enormous appeal for me. Although I have struggled with the qualitative – quantitative debate, I now agree with the conclusion put forth by Patton (2002):

> *This discussion has been explained with the understanding that a variety of methodological approaches are essential and credible, that the mixed methods approach can be appreciated and that the*

challenge is to suitably match methods to questions rather than adhering to some narrow methodological orthodoxy.

4.3. Ways of doing

Among qualitative approaches the practice of triangulation of methods was used in this study, in order to provide a more reliable range of perspectives. This is achieved by combining group interviews, observations, and in-depth interviews (Hudelson, 1994).

4.3.1. Interviews

Guidelines to the various interviews as described by Hudelson (1994) were followed. Interviewing began with a semi-structured interview format using a pre-planned interview guide. However, it became clear that the participants wanted to talk openly and freely to tell their stories. Consequently a two-way communication process between myself and the informants began to develop.

I believe a very important technique which I use when interviewing Aboriginal people is to be aware of my tone of voice, the speed at which I spoke and the clarity of the questions asked, and to allow the participant time to respond to the questions. These issues are important for a number of reasons. Firstly, there is a difference between the style of English used by educated researchers, and the Aboriginal English spoken in communities. The subtle differences of language mean that participants sometimes need to reflect on the question before they are comfortable that they know exactly what is being asked. More importantly, though, is the need to demonstrate respect for the community members. As an outsider, the responsibility rests with the researcher to communicate in a way that is appropriate in that community. Speaking in a respectful tone, speaking at a speed that is unhurried, and waiting respectfully for a response are appropriate communication styles that yield honest and rich responses.

Informed consent was gained from study participants before interviews took place. A tape recorder was used to record the interviews. Participants were assured that on the conclusion of transcribing the tapes the data collected would be erased so that the identity of the discussant could not be accidently disclosed. Handwritten notes were also taken and proved invaluable when taped information was difficult to hear.

Participants were assured that confidentiality would be strictly maintained in terms of my own personal knowledge regarding any information they provided.

4.3.2. Group Interviews

As focus groups are a particular type of group in terms of purpose, group size (usually six to eight people), composition and procedures, I chose a less formal group interview which can be held with family members living together, or members of different groups, commonly known as non-focus groups. The technique I used was unstructured open-ended interviewing (Hudelson, 1994).

The strengths of a group interview are that a lot of information can be brought forth in a limited time frame and they are beneficial in identifying beliefs, attitudes, behaviours and opinions in a community, and identifying the relevant questions and informants for further individual interviews.

As with interviews informed consent was gained from study participants before the group discussion took place. A tape recorder was used to record the group discussions and again participants were assured that the tapes would be erased when the data had been collated. The data was transcribed by using a word processing format; it was not entered into programs such as Epi Info or Nudist.

4.3.3. Consultation and community awareness

Research within Aboriginal communities is entirely dependent upon appropriate community consultation from the outset of a project. As I was employed in the health field before undertaking this research project in Cherbourg, I became aware of previous research designs where community consultation was not a strength, community members were aware of these issues of inconsistency with research design lacking in community consultation, these issues were a consistent concern for the community of Cherbourg.

Strong community consultation has been the key factor of this project from the outset. Before seeking the consent of respondents, information relating to the features of the study was circulated to community members who showed an interest in the research. This approach was essential to facilitate community commitment and participation

throughout all the research stages and to ensure ownership of the findings for future prevention initiatives. Information disseminated during the study was presented in a way the women could easily understand.

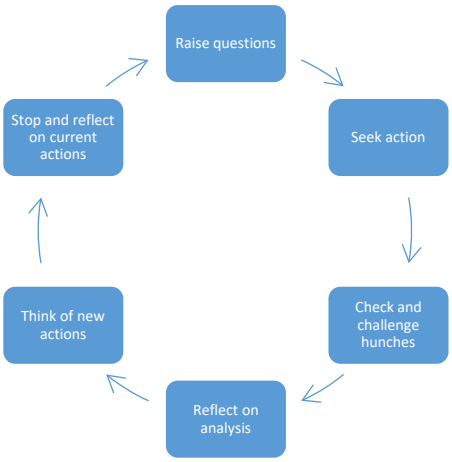
The success of research within Aboriginal communities is dependent upon a number of important considerations. These include the identity and reputation of the researcher, the use of appropriate protocols and processes in the identification and development of the research project, the setting of appropriate and achievable time frames for data collection, its subsequent evaluation and the manner in which results are disseminated.

In relation to these discussions it is noted that academic research is, by its very nature, a process that must remain external to the everyday lives of the participants involved. Even a simple conversation with a community member becomes more than just a conversation when an individual involved is known to the researcher. This remains true even when the researcher is Aboriginal. Indeed, Aboriginality itself brings a new level of dynamic to the relationship between researcher and community. For this reason discussions have taken place, and will continue, with the greatest sensitivity and the assurance of confidentiality. Confidentiality itself is something that needs to be demonstrated rather than simply promised. During my time at Cherbourg, I endeavoured to maintain this integrity to develop a relationship of trust with the community.

4.3.4. Reflection

Throughout my research approach I have reflected on current actions, raised a question, sought an answer, checked and challenged hunches (fieldwork) and considered the findings (analysis). This process is continued throughout most chapters within this thesis.

Figure 2: Simple research process



5. The Impact of Colonization on the health and wellbeing of Aboriginal Women

5.1. Introduction

Any discussion of health in the Aboriginal community must acknowledge the political and historical conditions of dispossession, from ancestral land, which in Australia are implicated in the poor health status of Aboriginal people. The social determinants that have underlined the past and current health status of Aboriginal people, have included a history of dispossession, racism, social exclusion and a legal framework supporting removal of children from families.

5.2. Colonisation and Dispossession

While colonialism and dispossession are the not the cause of all alcohol use among Indigenous Australians, we now know that drinking patterns are a response to this history. A similar response is also found among other Indigenous peoples from Canada and North America (Kirmayer et al., 2000).

In order to gain an understanding of the complex issues that confront Indigenous people (including unemployment, poverty, alcoholism, violence, poor health, disharmony and despair within the family and the community), one must have an insight into the mechanisms of the past government legislation and its indelible impact on the lives of all Indigenous people (O'Shane, 1995).

Each state had its own acts and government policies relating to Aboriginal people. If one was deemed to be a “half caste” then the individual would be removed from their parents, family and community and sent to live with non-Indigenous people. This decision was made by the Aboriginal Protector who controlled the Aboriginal people throughout Queensland and the reserves within each state (O'Shane, 1995). The power given to the Protector gave him the right to decide on who could associate with whom, permission to marry, permission to leave the reserve, and management of bank accounts, wills, property and debts and wages.

Moran (2005) has stated that, after the Second World War the Australian Government introduced a policy under which Aboriginal people were to be 'assimilated' into the wider European population and its way of life. However, it was the belief that Aboriginality would meet a timely end (Rowley, 1970). Part of the policy involved the widespread forced removal of children from their families now known as the Stolen Generations (Human Rights and Equal Opportunity Commission, 1997).

The policy of assimilation had a devastating impact on Aboriginal families and their ways of life, the effects of which continue to resonate today. This includes the high level of mental health problems experienced by Indigenous Australians, and the absence of parenting models resulting in unacceptably high levels of child abuse and neglect, which many people attribute to this period (Brady et al., 2002).

Since the nineteenth century, to facilitate white migration, legislation was enacted which caused Indigenous people to be dispossessed of their homelands by force and incarcerated with people from other areas into new settlements provided by Government or church organisations. Further legislation throughout the twentieth century built upon this foundation of dispossession, and the policies and the laws that enabled its occurrence have denied Aboriginal people the opportunity to determine their own future or respond to the problems of their communities (Gale and Brookman, 1975, Najman, 2006, Atkinson, 1990).

It is stated by Atkinson (1990)

> *"that any recommendations for preventive strategies must be based on a clear understanding of the impact of colonisation on a nation of people whose cultural and spiritual values were radically different from the colonisers and the trauma and injury, which followed within Aboriginal Australia."*

The growing momentum brought about by the Indigenous rights movement and the implementation of these policies saw the rise of national Indigenous representative groups and community-controlled health and substance use services (Chenhall, 2007). During the 1990s, the Council for Aboriginal Reconciliation was established and the Aboriginal Reconciliation Act passed (Australian Government, 1991).

In 2007, the Australian Labor Party was elected to Government and committed itself to 'Closing the Gap' between Indigenous and non-Indigenous Australians. In February 2008, the Prime Minister honoured his pledge to issue a formal apology to Indigenous Australians for the past wrongs committed against them through the policies of former governments (Rudd, 2008). The symbolic apology was intended to mark a new era of reconciliation and partnership between Government and Indigenous Australians in which practical objectives could in turn be achieved.

5.3. Role of Aboriginal women after colonization

Aboriginal women have been particularly affected by this removal and it has been a major causative factor in their adoption of lifestyles characterised by the misuse of alcohol and drugs. Koutsounadis (1980) suggests and Langton (1993) agrees, that as a result of dispossession, Aboriginal women lost the ability to learn and speak their language, lost their sense of identity, their heritage and self-esteem. These losses under the force of the European invasion resulted in the breakdown of tribal systems, including kinship systems, economic systems, political systems and religious and spiritual belief systems.

Partly, this was achieved by forcing Aboriginal women to take up economic and sexual roles in European frontier settlements:

> *Aboriginal women played a pivotal role in the expansion of the European economy, by providing all the services which normally would have been supplied by the wives, mothers, sisters, and daughters who were not to join their menfolk until the wilderness had been tamed, and some semblance of civilisation created for their protection (Saggers and Gray, 1991)*

All this placed them in an environment which was immersed in violence, alcoholism, and abuse (Langton, 1993). As Kum Sing (1993) suggests, the world of an Aboriginal person is entrenched with racism and discrimination, and as a survival technique under these deplorable conditions many use alcohol and drugs to cope.

The vignette below is a brief snapshot of the experiences lived by a very strong resilient Aboriginal woman.

Rosie's Story

During Rosie's mid -forties she learned that she was not the eldest of two children but was the second youngest of definitely nine children, Rosie lingered with this new knowledge, as there was a possibility that there were another two children born to her beautiful mother. Rosie's mother Doreen was an amazing woman who was self-taught and educated. Doreen, being a survivor of the stolen generation, was removed from her mother (Gracie) in 1923 under the Infant Life Protection Act in Queensland.

She was taken at birth from Gracie and placed into a nursing home in Toowong, Brisbane. Doreen was eventually taken in and cared for by a doctor and his family living in Ithica, an inner-city suburb of Brisbane. When Doreen was twelve years of age, Gracie sought permission from the Aboriginal Protector in Longreach for the return of Doreen, her eldest child, to be placed back into her care. Gracie needed Doreen to help care for her younger siblings whilst she went to work as a domestic on a pastoral property nearest the town in which they lived.

At thirteen years of age Doreen was taken to work as a domestic on the same pastoral property as Gracie, and from that time on Doreen was raped by the owner of the property. He fathered the two infants that Doreen gave birth to; both babies were removed from her as soon as they were born and sent to England.

For Doreen this was the beginning of a journey of fear, love, kindness, bitterness, hate, secrecy and many mixed emotions that lead her into a life of searching, not only for her children but for her own identity. As with many survivors of the stolen generation, they kept looking for the nurturing and love that they did not receive from their own birth mothers. These searches lead to more children being born to Doreen who were all removed from her and placed into either foster care or institutionalized in an orphanage.

The removal of her children was not because she was not a good mother; it was due to the fact that her babies were fathered by white men and had fair skin. Under the Assimilation Policy, Aboriginal children with fair skin could be removed from their families with the expectation to be assimilated into the mainstream population. The loss of Doreen's children lead her to suffer from deep grief, loss, and trauma which lasted for the rest of her life, along with several severe chronic diseases which contributed to her death in 1995. In hindsight Doreen's family now realize that she not only suffered from chronic illnesses but she also had post-traumatic stress disorder (PTSD) which was either diagnosed or undiagnosed and lasted a lifetime (Lesley Frazer, personal communication, 1994).

5.4. Causal links of ill-health

As a response to the devastating effects of colonialism, including dispossession, Reynolds (1982) noted the severity of illness and death resulting from disease and confrontation from the European colonists. Many Indigenous people continue to deal with the legacy of dispossession and the health of the individual; family and community reflect its greatest impact (Saggers and Gray, 1998, Brady, 2002). The health impacts of such control led to a low sense of belonging and self-worth, low confidence, depression and introduced diseases.

It is stated in the NAHS Report (National Aboriginal Health Strategy Working Party, 1989): “the impact of the colonisation process and the consequences of dispossession social disruption, dispersal, loss of freedom, loss of culture and self-autonomy have been devastating and has been the cause of overwhelming psychological distress and trauma.” Aboriginal people in Australia are poorer, experience greater unemployment, have lower educational attainment, live in poorer housing and have less access to facilities taken for granted by mainstream Australians.

As a result of cultural discontinuity, Aboriginal People from Canada and North America have also lost confidence in what they knew and understood and how they valued their own identity as human beings. Along with Aboriginal people from Australia, the First Nation and Native American people may feel abandoned and alcohol misuse is a contributing factor to a wide range of health and social problems, which include violence social disorder family breakdown child neglect as well as loss of income or diversion of income to purchase alcohol and other substances, and high levels of imprisonment. Cultural discontinuity and oppression, as noted by Kirmayer et al. (2000), has been linked to high rates of depression, alcoholism, suicide, and violence.

5.5. History of availability of alcohol

Much of the literature examining the problems of ill-health in Aboriginal communities, in Australia and elsewhere, describes casual links that begin with dispossession, and particularly the relationship between dispossession and alcohol misuse (Brady, 1993). While colonialism and dispossession are the not the cause of all alcohol use among Indigenous Australians, drinking patterns are a response to this history, as found among other indigenous peoples (Kirmayer et al., 2000) The existing patterns of

alcohol use among Aboriginal people, and the contributing dynamics that influenced the developing patterns cannot be understood apart from the historical context in which they have occurred.

It is discussed by Brady (1991) and supported by Saggers and Gray (1998) that Aboriginal Australians were exposed to alcohol prior to European contact. However, as a result of the landing of the colonizers, the volume and the promptness to supply alcoholic drinks increased significantly. Alcohol quickly became the basis for social and economic colonial life within Australia, with many Aboriginal people developing an acquired taste for alcohol (Lewis, 1992).

The behaviours that developed from the consumption of alcohol suited the interests of the colonials who reportedly used alcohol in exchange for sex and or labour with Aboriginal people, especially women. As a result of legislation passed in New South Wales in 1869 and in Western Australia in 1880 with the Wines, Beer and Spirit Act alcohol was prohibited to Aborigines; (Saggers and Gray, 1991). This legislation was justified as an attempt to protect Aboriginals from the same substance that had recently been introduced as part of the means of conquering them.

Similarly, the Queensland Government enacted legislation to prohibit the sale of opium and alcohol to the Aboriginal population (Parliament of Queensland, 1897). This Act, titled the Restriction of Opium and Protection of Natives Act, remained in force until the 1930's. The intent was to promote the Government's policies and pacify the emerging outcry by Churches and other concerned groups about the plight of the population and to provide the legal basis to safeguard the health of the Aboriginal people. However, the evolving Assimilation policies of Governments further destabilised the fragile society of the Aboriginal people.

The 'dog tag' was the name given to the citizenship certificate. Citizenship was perceived by the Aborigines as the right to drink, and to gain the status of equality with white men, but it did not give them the right to enter ale houses, or hotels. In the 1967 referendum, Australians voted overwhelming to amend the constitution to allow the Commonwealth to make laws for Aboriginal people and to include them in the census.

Contrary to popular belief, after the 1967 Referendum was passed, Aborigines were not automatically given the right to drink alcohol. The decision to allow alcohol

consumption by Aborigines was the responsibility of the different State Government and not a Federal concern.

5.6. Understanding the misuse of alcohol: patterns of alcohol related harms

Historical influences cannot be overestimated in their impact on contemporary Aboriginal drinking patterns, or indeed on any aspect of Aboriginal Health. As a response to the devastating effects of colonialism, including dispossession, Reynolds (1982) noted the severity of illness and death resulting from disease and confrontation from the European colonists. Alcohol became somewhat of a cure-all for Indigenous people's pain, with many using it as a means of escape and comfort (Saggers and Gray, 1998, Najman, 2006). It was not long before the harmful effects of alcohol impacted on the lives of Aboriginal people.

Speaking of a parallel experience in American Indians, Dozier (1966) also states:

> *It is clear that the causes of Indian drinking must be sought in historical, social and cultural circumstances. Among all those who drink alcohol to excess whether Indian or non-Indian, there is a background of emotional troubles, frustrations, and disappointments. Alcohol under these circumstances temporarily gives a sense of superiority and confidence, while dulling the senses so that the unpleasantness's of life may be forgotten.*

In Australia the final Report of the Royal Commission into the Aboriginal Deaths in Custody (Dodson et al., 1998) stated:

> *The relative powerlessness of Aboriginal people is very much to the fore. So much of their current situation vis-à-vis alcohol use can be understood in these terms. Dispossession from lands, interference with kinship systems, destruction of economic resources, weakening of social control mechanisms all are signs of dis-empowerment. Alcohol and other drugs do not play an essentially casual role in these processes; the causes are essentially political, economic and historical in nature. Alcohol use and self-destructive behaviours*

reflect the individual (and communities') response to, and expression of, this dis-empowerment.

The pattern of Aboriginal drinking in the early contact period closely resembled that of their European counterparts. In colonial Queensland, for example, references to the degrading impact of alcohol on the non-aboriginal population appear frequently:

> *The white male drinking fashion of "lambing down" or "knocking down" a cheque meant that men make a business of being drunk while they are drinking alcohol, and allow no interval of sobriety to intervene until they have finished their money (Saggers and Gray, 1991).*

Saggers and Gray (1991), maintain that there are social rules for drinking in Aboriginal communities and such drinking serves a number of functions. The social rules that take over during drinking episodes allow for the suspension of other rules of conduct that apply under normal circumstances. Drinking rules allow for the open expression of aggression through violent behaviours, sexual freedom and non-responsibility. Is this change of social rules the beginning of binge drinking behaviours previously witnessed by Aboriginal males through observations of *lambing down a cheque.* This timeout and non-accountability serves a valuable purpose in a culture undergoing rapid change. However, the behaviour that accompanies such time out becomes untenable when it is chronic and spreads throughout an entire community. The physical and social consequences of alcohol use and abuse have led to a number of studies exploring the susceptibility of Aboriginal people, and the historical, socio-cultural and cross-cultural conditions leading to Aboriginal misuse (Saggers and Gray, 1998).

Political conditions leading to high levels of alcohol use by Aboriginal people and the cultural aspects of drinking in the Aboriginal communities have also been well covered (Hazlehurst, 1994). Despite the number of studies, various threads remain unlinked.

A recent review by Corti and Ibraham (1990), argued that the changing status of women has made it more acceptable for women to drink socially. Women appear to be more susceptible to the toxic effects the alcohol compared with men and appear to be drinking more heavily than their male counterparts. Factors contributing to this

change include more independence, more money as more women may join the work force, and or less money as women may find themselves being placed in a position where the income has decreased i.e. a loss of their job, loss of their partner and loss of their family. The changing behavioural patterns and the continuation of alcohol consumption by women may be seen as a direct result of the social acceptance of women drinking and combining their drinking activities within the boundaries of the home and family environment.

The introduction of drive-in bottle shops, increased trading hours for licensed premises and the sale of alcohol in supermarkets has contributed to de-stigmatising the buying of alcohol which has become an ordinary consumer product for women. Advertising of alcohol is portrayed as a glamorous, fashionable, socially acceptable and a desirable product. It is argued by Corti and Ibraham (1990), that alcoholic beverage advertising reinforces and reflects community trends, thus normalising and sanitising alcohol consumption. All these comments are true for Aboriginal women who are acutely aware that any stigma associated with the behaviour of White Australian women will count tenfold for themselves.

5.7. Alcohol culture and life cycle

The literature describes a sense in which Aboriginal people drink alcohol as an expression of identity and culture. This issue has been discussed in the past, the impression is created that the 'drinking' characteristic of so many Aboriginal communities is a part of Aboriginal culture. This confuses and conflates a number of different cultural levels within which people exist. Being a drinker is not equivalent to being an Aboriginal in any sense, traditional or contemporary. However, when Aboriginal people enter into a drinking cycle of behaviour, there is a sense in which groups identify and belonging is based on their behaviour.

The problem of alcohol overuse in Aboriginal communities is the paramount concern of governments, police and justice bodies, and the general public and Aboriginal people themselves recognise the overuse of alcohol in their community as a major concern that is linked directly to a large number of health and social problems (Pearson, 2001).

5.8. Harmful and Hazardous Levels of Alcohol Consumption

Throughout my research journey I have witnessed children move from adolescence to young adulthood, they face major changes not just developmentally, but emotional and physically. Their transition into puberty and adolescence brings about a desire for independence. I have observed many early teenagers turn to risk taking behaviours and experimentation as they navigate through their rite of passage into adulthood, which can eventually lead to drinking.

There has been substantial research on Aboriginal consumption patterns. The Australian Council on Alcohol and Other Drugs (1990) states that the level of alcohol consumption among Aboriginal people depends on where they live. Aboriginal people living in town and fringe camps drink most frequently while those in remote areas are more likely to drink in episodes or intermittently. The drinking pattern by Aboriginal people is strongly associated with the availability of alcohol, paydays, weekends and financial resources. Hunter (1993c) suggests that age predicts both drinking status and pattern of consumption for both male and female Aborigines. Among young males, drinking alcohol is almost universal but the proportions of young females are also increasing. Binge drinking is common among young males and is increasing among young women.

The literature on alcohol abuse tends to confuse alcohol use at harmful levels with alcoholism. Alcohol use in Aboriginal communities is characterised by recurrent binge drinking, accompanied by violent and socially conflicting behaviour (Kelly and Kowalyszyn, 2003). There appears to be a clear transition stage for many youths that leads them into binge drinking at an early age, similar to the patterns described for Native American youth (Levy and Kunitz, 1974).

The report also recognises that a large proportion of Aboriginal people, particularly women, do not drink alcohol. However, the majority of Aboriginal people who do drink do so at levels which are considerably higher than for the broader population, and at levels which are considered hazardous or harmful to their health (AIHW, 2011). Also, a large number of the episodes of violence, arrests and medical treatments in any community are linked to disproportionately small number of the community's members.

Table 1: NHMRC Guidelines for reducing risk of alcohol related harms

Guideline 1 Reducing the risk of alcohol-related harm over the course of a lifetime, the lifetime risk of harm from drinking alcohol increases with the amount consumed. For healthy men and women, drinking no more than two standard drinks on any day reduces the lifetime risk of harm from alcohol-related disease or injury.	Guideline 2 Reducing the risk of injury on a single occasion of drinking on a single occasion of drinking, the risk of alcohol-related injury increases with the amount consumed. For healthy men and women, drinking no more than four standard drinks on a single occasion reduces the risk of alcohol-related injury arising from that occasion.
Guideline 3 Children and young people under 18 years of age For children and young people under 18 years of age, not drinking alcohol is the safest option. A Parents and carers should be advised that children under 15 years of age are at the greatest risk of harm from drinking and that for this age group, not drinking alcohol is especially important. B For young people aged 15−17 years, the safest option is to delay the initiation of drinking for as long as possible	**Guideline 4** **Pregnancy and breastfeeding maternal alcohol consumption can harm the developing foetus or breastfeeding baby.** **A For women who are pregnant or planning a pregnancy, not drinking is the safest option.** **B For women who are breastfeeding, not drinking is the safest option.**

However, it is stated by the National Health & Medical Health Research Council (2009) that alcohol consumption can be measured. The guidelines for reducing the risk of alcohol related harm over the course of a lifetime are set out in Table 1.

5.9. Previous research

The data from which our understanding of Aboriginal alcohol use is derived are collected according to a small number of structured approaches and are filtered through an equally limited number of interpretive models.

Maggie Brady (1998) suggests that early information regarding the use of alcohol by Aboriginal people was gathered anecdotally, as a result of expressed concerns and experiences of church and welfare workers and their paternalism rather than as a result of systematic research undertaken in that particular area. Other early finding on alcohol use came about as an outcome of systematic study but from fieldwork which had other objectives than alcohol use.

The Australian Council on Alcohol and Other Drugs (1990)states:

> *Quantifying Aboriginal alcohol use is a difficult process and has been attempted using a variety of techniques. Owing to differences in the methodologies employed a number of factors should be considered when interpreting and generalising results.*

A majority of the more recent studies exploring issues of Aboriginal alcohol use have utilised the population census data gathered by the Australian Bureau of Statistics (ABS). The data considered necessary to the objectives of each study are drawn from the large body of data held by the ABS and State and Federal Health Registries. These data are collected as part of a nationwide survey of household residents and represents, theoretically, the entire population at a specific slice of time. In 1994 the ABS did a household survey which provided a comprehensive overview of Aboriginal and Torres Strait Islander health and welfare in Australia (Australian Bureau of Statistics, 1994). This data is valuable as a means of identifying the patterns of disease across whole populations, but it does not adequately describe the problems associated with specific diseases or minority groups.

The use of alcohol is particularly difficult to discern through these large population data sets, as illness associated with alcohol abuse is rarely identified as such. Self-reporting of alcohol use on a lengthy questionnaire is also unlikely to be reliable. There are a number of problems with many statistically based studies of health problems, including alcohol use, in Aboriginal communities. Morbidity figures relating to all Aboriginal ill-health are extremely inadequate (Australian Bureau of Statistics, 1994). Aboriginality has only recently been identified on death certificates (Australian Bureau of Statistics, 1997).

Household surveys are not likely to capture a representative sample of Aboriginal residents in any given area because of high levels of transience, visiting with families, lack of permanent residence and so on. Furthermore, Aboriginal people are less likely than non-Aboriginal Australians to trust the confidentiality claims of government agents in relation to data collected. It is also the case that alcohol research has been predominantly based on self-reporting. This is problematic when dealing with sensitive issues within any cultural group. These generic problems are multiplied for subjects who distrust the goals of research and the integrity of individual researchers, Aboriginal people are also acutely aware of the impact of stereotypic views of Aboriginality and are reluctant to participate in research in ways, they expect, that may perpetuate these stereotypes.

Statistical information alone is not going to provide the detail necessary to fully understand the complex cultural, political and spiritual issues involved in describing the link between Aboriginality and the overuse of alcohol.[55]

5.10. Conclusion

The social determinants that have underlined the past and current health status of Aboriginal people, have included a history of dispossession, racism, social exclusion and a legal framework supporting removal of children from families. While colonialism and dispossession are the not the cause of all alcohol use among Indigenous Australians, we now know that drinking patterns are a response to this history.

After working in Aboriginal communities for three decades, three topics of concern have come to light for me: firstly, the devastating effect that substance misuse has on Aboriginal people and their communities; secondly, the levels of alcohol consumed by women; thirdly, the difficulties faced by individuals, families and communities affected by alcohol. The following chapter is about alcohol use by pregnant women, and its effect on infants.

6. Alcohol consumption by pregnant women

6.1. Introduction

This chapter is about alcohol consumption by pregnant women and reviews the behavioural and cognitive effects of PAE and the devastating consequences for the developing embryo and foetus.

FASD was identified by a French clinician, Lemoine. It is a medical diagnosis that refers to a set of alcohol related disabilities which are associated with the use of alcohol during pregnancy (Lemoine et al., 1968). It has been identified in the literature that children born to a drinking mother will be more severely damaged, as her alcoholism depletes her body of resources to nourish the foetus, as noted by Tomison (1996).

During the past decade, interested researchers have attempted to determine the extent to which women who drink before and during their pregnancy may be placing their unborn child at risk of developing mild, or severe disabilities that may be related to FAS (May and Gossage, 2001, Hayes, 2001b, Chudley, 2005) concur that the essential contributing factor in this discussion is about alcohol use by pregnant women, as FASD is only found in infants where alcohol exposure in-utero has occurred (Chudley, 2005).

A review by Lipson (1994) indicates that alcohol can have a variety of effects on the unborn foetus which are related to the amount of alcohol consumed by the woman, the stage during her pregnancy when the alcohol was consumed, and the genetic make-up of the mother and child. Alcohol has the capacity to cause serious birth defects and as Abel (1984) has noted, no safe level of alcohol consumption in pregnancy has yet been established. The child who has been diagnosed with FAS may present with a wide variety of physical and behavioural effects, such as prenatal and postnatal growth restriction, central nervous system (CNS) dysfunction, developmental delays, behavioural dysfunction, learning disabilities and other intellectual impairments.

There are emerging concerns relating to FASD in Aboriginal communities and the intergenerational impact of the historical conditions of dispossession along with the link of historical abuse and trauma experienced by individuals.

6.2. Background to FASD

In 1968, Paul Lemoine a French paediatrician, first described dysmorphic facial features and growth delays in infants born to mothers who drank alcohol during their pregnancies.[13]

The term FAS first appeared in two classic papers authored by David Smith, Ken Jones, Christy Ulleland and Ann Streissguth in 1973.

This team of clinicians from Seattle in Washington State, USA, described:

I. comparable characteristics present in eight unrelated infants

II. these infants were from three different ethnic backgrounds

III. these infants were all born to mothers who were chronic alcoholics.

The recognition that PAE causes facial dysmorphology, growth delays and CNS abnormalities dated from this time. Thirty years on and the research on FAS is still identifying the teratogenic effects of alcohol on the developing foetus (Massey and Massey, 2007). Results of early research undertaken by Jones, have clearly described the presence of a syndrome of neuro-developmental, neuro-cognitive and neuro-behavioural deficits that persist throughout the lifespan, in spite of race or ethnic origin (Jones and Smith, 1973, Jones et al., 1973)

To date, FASD is commonly seen as a pattern of physical malformations, growth deficiencies and growth retardation, coupled with intellectual and developmental disabilities. FAS is a leading known cause of mental retardation in the Western world (Mattson and Riley, 1998, Streissguth and O'Malley, 2000, Abel and Sokol, 1987). The behavioural and cognitive effects of maternal alcohol consumption during pregnancy may have devastating detrimental outcomes for the foetus. A review of neurobehavioral deficits in children states that, in addition to structural abnormalities

and growth deficits, FAS is associated with a broad spectrum of neurobehavioral anomalies (O'Malley, 2007, Sokol et al., 2003).

Sokol et al. (2003) also refers to a constellation of abnormalities both physical and psychological, and notes that FASD is not a diagnosis, but an umbrella term which incorporates FASD, FAS, FAE and Alcohol Related Neuro-developmental Disorder.

6.3. What is FASD?

As stated by the FASD Diagnostic & Prevention Network[3], FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. An individual would not receive a diagnosis of FASD. Four diagnoses fall under the umbrella of FASD: FAS, Partial FAS, Static Encephalopathy/Alcohol Exposed (SE/AE) and Neurobehavioral Disorder/Alcohol Exposed (ND/AE).

Firstly, to understand the constellation of abnormalities one needs to have an understanding of what is FASD is. It is stated by O'Malley (2007) that:

1. *"The **dosage** of alcohol (the agent) even a low dosage may be teratogenic.*

2. *The **timing** (trimester) of the exposure during pregnancy. Each trimester of pregnancy has specific teratogenic effects, the 1st trimester, facial dysmorphology and growth deficiencies and the 2nd and 3rd trimester exposure has the most insidious effect on CNS development, especially the neurotransmitter development.*

3. *Medical factors particular to the mother (**or host**). These include the chronicity of alcoholism in the mother and her general nutritional status, as well as the protective factor of her specific genetic endowment. The group of infants and children who did not show full FAS were initially described as displaying Foetal Alcohol Effects (FAE)*"

[3] FASD Diagnostic & Prevention Network, Centre on Human Development & Disability University of Washington, Seattle, WA.

6.3.1. Difficulties experienced by FAS affected individuals

Individuals living with FASD may experience all or some of the following intellectual, physical, social, and learning difficulties amongst others; including primary disabilities and secondary disabilities:

Attentional difficulties (distractibility)

- Inability to connect
- A lack of understanding of social cues and relationships
- Trouble making friends and easily influenced
- A poor sense of personal boundaries
- Poor impulse control
- Even minor changes in routine can be overwhelming
- Poor and inconsistent memory function, leading to a need to be retaught the same concepts over and over again
- Trouble remembering where things are
- Difficulty remembering and understanding directions (especially if lengthy or complicated)
- Lethargic or hyperactive
- Demanding of lots of one-to-one attention
- Difficulty telling right from wrong
- Wanting lots of physical contact
- Giving an appearance of capability without actually having the abilities that they seem to have (illusion of competency)
- Difficulty separating fact from fantasy
- Low self-esteem, Low motivation
- Vision, hearing, heart, and growth problems and deficits.

O'Malley (2007) reports that there are a number of psychiatric conditions associated with FAS. These include Attention Deficit Hyperactivity Disorder, Conduct Disorder, Depression, Psychosis and Substance Abuse. They add that issues such as

decreased sucking response, motor immaturity, increased irritability and disturbance in sleep patterns associated with the condition in the postnatal period may significantly affect the attachment between the infant and mother, leading to later psychiatric issues such as depression.

A study undertaken by Streissguth et al. (2004) of the social impact of FASD in the US found that individuals aged between six and fifty-one years of age affected by FASD and have the following social and emotional health problems:

> *90% of individuals (6 years and over) have experienced mental health problems such as cognitive disorders, psychiatric illness or psychological dysfunction; 30% of individuals (12 years and over) had experienced alcohol and drug use disorders; 60% (12 years and over) had disrupted school experiences; with 50% of youth aged 12 years and over exhibited inappropriate sexual behaviour, along with 60% of the individuals have been in conflict with the law and half this group had experienced confinement either in prison or substance rehabilitation setting.*

6.3.2. Associated Secondary Disabilities

Until 1996, efforts to identify children with FAS and to prevent its associated secondary disabilities through early diagnosis and interventions were constrained by the lack of efficient and effective surveillance and screening tools (Stratton et al., 1996). As a consequence there has been little attention given to the prevention of secondary disabilities for affected children and youth within the health and education sectors.

In 1996 the U.S. Institute of Medicine released detailed diagnostic criteria for partial FAS/FAE which identifies a complex pattern of behavioural and or cognitive dysfunction that is unrelated to developmental maturity or to family or home environment and includes the following (Stratton et al., 1996).

Table 2: Secondary disabilities associated with FASD

Secondary disabilities	
difficulty in learning	problems relating to others
poor school performance	deficits in language
poor mathematics skills	problems with attention
problems with memory	problems with judgment
deficits in ability for abstract thinking	

Adaptive functioning – young people with impaired adaptive functioning have difficulty meeting the expected age-appropriate and cultural norms for personal independence and social responsibility, despite appearance of physical maturity.

Language – young people with language impairment have trouble understanding and producing language (oral language competence), despite sometimes being extremely verbose.

Attention – young people with attention deficits and hyperactivity can have difficulty in sustaining focus on conversations or tasks.

Reasoning – young people may be unable to engage in abstract thinking, for example about concepts such as time and personal goals and have difficulty with executive and other higher order functioning.

Memory – young people may have difficulty in free recall of information critical to legal proceedings and have difficulty in learning new information. [23]

It is well documented that deficits in adaptive and executive functioning are thought to play a central role in one's cognitive flexibility and negatively impact both reasoning ability and capacity to engage in socially appropriate behaviour. Most notably, among children with FASD, levels of adaptive and executive functioning are often lower than that accounted for by general intellectual ability (Chudley, 2005).

The teratogenic effects of prenatal exposure to alcohol can have devastating outcomes on the developing embryo and foetus in many different ways cause a whole spectrum of disorders.

As a result of discussions relating to the necessity to improve accuracy and precision when recording the diagnostic features of FASD, it has been agreed by FASD specialists after critically reviewing and evaluating published and practical methods for the potential screening of suspected cases, the epidemiological characteristics such as sensitivity, specificity, positive and negative predictive values are now essential when establishing guidelines that incorporate common numeric language for communicating outcomes in medical records and in the medical literature (Hoyme et al., 2005). In 2000, Astley and Clarren (2001) developed a 4 Digit Diagnostic Code to demonstrate how the two measures of the FAS Facial Phenotype correlate with brain function and structure.

The broad spectrum approach described above has led to a number of ways of identifying individuals affected by the disorder. Nulman et al. (2007) caution that the diagnosis may be difficult to ascertain with some of the behavioural abnormalities being slight rather than marked and that children affected by other developmental conditions such as phenylketonuria, fragile X syndrome, Turner Syndrome, Noonan Syndrome and Williams Syndrome often display similar physical and neuro-developmental abnormalities.

6.3.3. Diagnostic Criteria

In determining a diagnosis of FAS, the first identified criterion is alcohol exposure in the womb. According to the traditional diagnostic criteria (Astley, 2004), children may exhibit the following characteristics:

1. *"Delayed prenatal growth, postnatal growth, or both. Growth deficiency, for height, weight, head circumference (such delay must result in height and or weight below the 10th percentile).*

2. *CNS ….this can result in one or more of the following conditions being observed in the child: head circumference below the 3rd percentile; developmental delay or intellectual deficit/hyperactivity disorder.*

3. *A specific pattern of minor facial anomalies that includes short palpebral fissures, a complex lower facial malformation that is typified by epicanthal folds, a flat mid-face, short upturned nose, a smooth or a long philthrum and a thin upper lip. These features are sometimes not evident in infancy and may change during adolescence and become less evident in adulthood. Changes in pattern of facial features in an individual do not indicate that he or she no longer has FAS.*

4. *Some CNS damage, including microcephaly, tremors, hyperactivity, fine gross motor problems, attention deficits, learning disabilities, intellectual or cognitive impairments and or seizures.*

5. *Alcohol related birth defects to denote the presence of congenital anomalies known to be associated with a history of PAE.*

6. *Alcohol related neuro-development disorder requiring a confirmed history of parental alcohol exposure and evidence of CNS abnormalities."*

In reaching a decision that a child has been affected by alcohol exposure in-utero, it is important to explore the history of significant prenatal alcohol use. This is confirmed by the Canadian guidelines for FASD (Chudley, 2005), and supported by the United States diagnostic guidelines for FAS (Bower et al., 2009) along with the 4 digit diagnostic code offered by Astley (2004), which offers a more standardized, case-defined criteria than those published in previous guidelines in 1996. As suggested by the Institute of Medicine (Stratton et al., 1996) and Streissguth et al. (1996), two classifications of FAS are evident: one with and one without confirmed maternal alcohol consumption.

"FAS/FAE without a confirmed history of alcohol exposure: these patients have the same phenotype findings as above, but no history of alcohol can be confirmed.

Atypical FAS/FAE is when individuals have a phenotype that very nearly is complete for FAS and has a confirmed history of alcohol exposure, but lack growth deficiencies.

Features of FAS with confirmed maternal alcohol exposure are:

1. "*Continued maternal alcohol exposure*

2. *Evidence of characteristic pattern of facial anomalies including: short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface).*

3. *Evidence of growth retardation, in at least one of the following: low birth weight for gestational age, decelerating weight over time not due to other identified causes, disproportional low weight to height.*

4. *Evidence of CNS abnormalities in at least one of the following: decreased cranial size at birth, structural brain abnormalities (e.g., microcephaly, cerebellar hypoplasia, neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor hand eye coordination"*

All diagnoses under the umbrella indicate the same level of brain impairment - none is more significant than the other. FASD is a lifelong disability which includes a range of effects, including developmental, physical and behavioural symptoms[4].

6.4. Mechanisms of alcohol – related damage to the foetus

Excessive alcohol consumption by the mother during pregnancy is thought to be poisonous to the developing foetus in a number of ways. When a pregnant woman consumes alcohol, the alcohol enters her blood stream and is carried by the mother's blood into the developing foetus (Mattson and Riley, 1998). Alcohol directly crosses the placenta and blood brain barrier, it is directly toxic to the foetal brain. As a result, the brain of an exposed foetus may be reduced in size with significant reductions in grey matter being observed in the hippocampus, thalamus and globus pallidus brain regions (Nulman et al., 2007).

The amount of alcohol consumed during the first trimester has a substantial effect on the unborn child and is related to the frequency and timing of the use of alcohol (Little

[4] http://www.asantecentre.org/research.html

and Wendt, 1991). However, it is suggested by Barker (1998) that there are no safe limits of alcohol consumption by pregnant women and no safe time period during the pregnancy to consume alcohol. Research suggests that drinking even small levels of alcohol when one is pregnant may have damaging effects on the foetus. In the early stages of pregnancy just one session of five glasses of alcohol or two drinks per day in the later part of the pregnancy has been shown to cause alcohol related disabilities in the newborn (Little and Wendt, 1991). The risks of prematurity, small for gestational age and miscarriage as well as a wide variety of congenital abnormalities are all trebled in drinkers, and these should be regarded as non-specific risks of alcohol consumption (Sayers and Powers, 1997). Corti and Ibraham (1990) declared that other, not so visible, problems arising from alcohol consumption relate to breast cancer, gynaecological and obstetric problems.

A review by the The Arc (1992) states:

> *In pregnant women, alcohol is not only carried to all organs and tissues, but also to the placenta, where it easily crosses through the membrane separating maternal and foetal blood systems. In this way, alcohol is transported directly to the foetus and to all its developing tissues and organs. When a pregnant woman drinks alcohol, the concentration of alcohol in her unborn baby's bloodstream is the same levels as her own. However, the liver of a foetus cannot process alcohol at the same rate as the adult, which is one ounce of alcohol every two hours. High concentrations of alcohol, therefore, stay in the foetus longer, often for up to 24 hours. In fact, the unborn baby's blood alcohol concentration is even higher than the mothers during the second and third hour after a drink is consumed.*

Raymond et al. (2009) suggest that binge drinking patterns of alcohol during pregnancy are as important as standard levels of consumption in determining risk for later childhood mental health and learning problems. Evans et al. (2001) noted that:

> *Avon Longitudinal Study of Parents and Children investigated whether patterns of alcohol consumption are independently*

associated with child mental health and cognitive outcomes; whether there are gender differences in risk; and whether occasional episodes of higher levels of drinking carry any risk in the absence of regular daily drinking during pregnancy. The determination showed that maternal alcohol consumption of ≥4 drinks in a day on an occasional basis during pregnancy may increase risk for child mental health problems in the absence of moderate daily levels of drinking. The main risks seem to relate to hyperactivity and inattention problems.

In the event of poor nutritional status, mothers who are undernourished can attain higher blood alcohol levels with decreased capacity to metabolize alcohol. Short intervals between births is also associated with an increased risk of congenital malformations and severity of FAS. In addition, women who drink are also more likely to smoke heavily and to use other drugs, all of which may have a cumulative harmful effect on the developing foetus (Chomitz and et al., 1995).

Substance abuse during pregnancy has been shown to represent a serious threat to the foetus as rapidly developing tissues are particularly vulnerable to their effects. Health risks associated with drug use during pregnancy include low birth-weight, developmental delay, risks of increased perinatal mortality, and increased risk of complications during the pregnancy (Nathanielsz, 1999). Smoking during and after pregnancy can have many adverse effects on the child, and smoking rates are linked to alcohol use. Health risks of smoking during pregnancy are extensive. An important risk noted is the reduction in birth-weight of 200 grams that result in foetal retardation (McCormick et al., 1990).

6.5. Prevalence

FASD are costly, life-long disabilities. Older data suggested the prevalence of the disorder in the United States was 10 per 1,000 children; however, there are few current estimates based on larger, diverse population samples such as a cross-sectional study of 13,146 first-grade children in four regions of the United States. This study was undertaken by May et al. (2018) surveying between 2010 and 2016. The most conservative prevalence estimates for FASD, ranged from 11.3 to 50.0 per 1,000

children. Using a weighted approach, the estimated prevalence was 31.1 to 98.5 per 1,000 children.

FASD is causing concern as an emerging public health problem in Australia. An Australian National Council on Drugs Report notes that 11% of women surveyed had consumed more than two standard drinks per occasion and more than six standard drinks per week during their pregnancy. Fourteen percent of the women surveyed admitted to drinking five or more standard drinks per session during the three months prior to pregnancy and that half the pregnancies were unplanned. The report notes that it is estimated that at least 42% of Aboriginal and Torres Strait Islander women will have used alcohol whilst pregnant.

Although FASD has been comprehensively studied in North America, Canada and Europe since the syndrome was identified by Jones et al. (1973), the initial estimates of FASD prevalence in Australia were based on clinical accounts and unpublished records from obstetric hospitals (Lipson, 1994). To-date the prevalence rate in Australia is unknown, although there have been estimated prevalence based on the (Lilliwan Study) in Fitzroy Crossing W.A. (Fitzpatrick et al., 2012).

A separate study from Western Australia estimated the prevalence of FASD to be at a rate of 0.02 per 1000 for non-Indigenous children and 2.78 per 1000 for Indigenous children (Bower et al., 2000). The research undertaken in Western Australia (Fitzpatrick et al., 2012) no doubt will significantly contribute to the knowledge of FASD in Australia; it will also raise the awareness of the prevalence; and the impact of FASD that will identify the health consequences of maternal alcohol use in Australia. It has addressed the lack of baseline data in Australia for Aboriginal and Torres Strait Islanders who have been prenatally exposed to alcohol by carefully screening the Aboriginal and Torres Strait Islander populations. Peadon et al. (2011) continues to suggest that carefully screening will address the lack of baseline data in Australia for Aboriginal and Torres Strait Islanders who have been prenatally exposed to alcohol.

A prevalence study undertaken by Harris and Bucens (2003), estimated the general rate of FASD generally to be 0.68 per 1000 live births with the rate for Indigenous children estimated to be 1.87 per 1000.

As stated by the AIHW (2011), compared with non-Indigenous Australians, a higher proportion of Indigenous Australians abstain from both alcohol use and binge drinking. The data show that:

• In 2008, nearly three in ten (29%) Indigenous Australians did not drink in the last 12 months—almost double the rate of non-Indigenous Australians (15%)

• Indigenous Australians were twice as likely as non-Indigenous Australians to binge drink (17% and 8% respectively) in 2004-05.

• The proportion of Indigenous (15%) and non-Indigenous people (14%) who drank at long-term (chronic), risky or high-risk levels was similar in 2008.

• Alcohol consumption patterns for Indigenous Australians varied by sex in 2008, with a higher proportion of men than women drinking alcohol, and consuming it at risky levels

• There was a decline in the proportion of Indigenous people who abstained from alcohol between 2002 (31%) and 2008 (27%).

6.6. FAS in Aboriginal communities

Evidence pointing to high rates of alcohol use by women in the Indigenous community suggests it is likely that children as a consequence of alcohol exposure in-utero will have disturbing developmental disorders caused by PAE. A study carried out by Bower et al. (1989) noted a high occurrence of FAS amongst Aboriginal births. Lancaster (1989) postulates that malformation rates are higher among Aboriginal people than non-Aboriginal people. Significant differences were noted for some congenital malformations including microcephalus; several types of congenital heart defects; cleft lip with or without cleft palate and talipes (Lancaster, 1989). However, the extent of the effect of alcohol on Aboriginal pregnancy outcomes has not been determined.

The experiences of the Aboriginal children from the ‘stolen generation’ in Australia are comparative to the viewpoint by Aboriginal authors Fournier and Crey (1997), who contend that the association between intergenerational trauma that is the result of the abuse experienced in residential schools in Canada and North America and the introduction of alcohol into communities have collectively contributed to high rates of

FASD and other related illnesses among the people. Evidence of high rates of alcohol use by women in the Indigenous communities in Canada suggests it is likely that many children will have developmental problems as a consequence (Tait, 2003).

Community health workers, nurses and other allied health professionals express concern about the birth defects they are observing within the children of the Aboriginal and Torres Strait Islander communities, and to a lesser extent in the broader Australian community, which continue to be ignored (Deceased, personal communication, 2017). The ANCD Report recommend improved screening and diagnostic tools to identify the condition and improve health workforce skills in relation to assessing and managing individuals affected by FASD. It also advocated improved screening for alcohol abuse by pregnant women and the development of harm reduction strategies for drinking in pregnancy along with increased support services for affected individuals and their families. The identification of alcohol use by pregnant women requires an in-depth understanding of how the history of use relates to relationships, conception and childbearing (Russell, 1985, Burd and Moffatt, 1994).

Local initiatives originating from Aboriginal and Torres Strait Islander communities to address the issue are also worthy of note and a source of inspiration. *Marulu* meaning “precious, worth keeping” is a model of diagnosis and management of FASD, which had its origin in the 2008 Women’s Bush Meeting of the Fitzroy Valley communities (Fitzpatrick et al., 2012), and supports parents and carers of affected children. Aboriginal organisations then partnered with research and clinical groups from Sydney to conduct a FASD prevalence study. This commenced in 2010 following extensive community consultation and receipt of community consent. Data from this study are still being collected and will be used by the community to advocate for improved services and new models of health care. This will be the first study to ascertain FASD prevalence in Australia using a rigorous research design (Fitzpatrick et al., 2012).

6.7. Women’s knowledge and attitudes to alcohol use in pregnancy

Establishing the history of alcohol consumption is one of the most difficult issues in diagnosing FAS. The pregnant woman who consumes alcohol is not always easily identified. Women are not forthright about their drinking habits nor are they necessarily able to recall the precise quantities and timing of their drinks (Peadon et al., 2010).

However, in the absence of a specific biomarker to detect alcohol exposure, the history remains crucial in the diagnosis.

Approximately one-third of adult Australian women report drinking at least weekly and this pattern is most frequently reported by women of childbearing age. Although the AIHW maintains that most of these women drink at safe levels, a minority will develop significant problems such as alcohol abuse or dependence; 11 per cent drink at risky levels for alcohol-related harm over a lifetime, 30 per cent drink at risky level for risk of injury on a single occasion and 5 per cent of women report drinking daily (AIHW, 2011). The NHMRC noted in 2009 that high levels of alcohol consumed by the majority of Australians will pose a health risk, and that young women drinking at risky and high levels has increased**.**

Sterling Clarren (2005) states that many women are aware that heavy drinking during pregnancy can cause birth defects, but many do not realise that moderate or even light drinking may also cause harm to the foetus. In fact, no level of alcohol use during pregnancy has been proven safe. It is therefore, recommended by NHMRC (2009) in Australia that pregnant women abstain from drinking alcohol during their pregnancy.

In 2004, members of the Ministerial Council on Drug Strategy (MCDS) agreed that the Inter Governmental Council on Drugs (IGCD) should form a working party to provide advice about FASD, specifically of recent developments, both in Australia and internationally, that would inform policies to address issues associated with FASD. Women in their childbearing years and pregnant women might choose not to use alcohol or other drugs if they were informed about the harmful outcome that alcohol use can have on a developing foetus: consequences that last a lifetime, placing the newborn infant's intellectual and social opportunities at risk.

The majority of women are not aware that alcohol is a teratogen responsible for a range of abnormalities including FASD. Colvin et al. (2007) state that 47% of Australian women do not plan their pregnancies As a result of unplanned pregnancies it is possible that many women unintentionally expose their unborn child to the teratogenic affects of alcohol before they are aware of their pregnancy. It is additionally noted though that 24% of Australian intend to drink alcohol if pregnant (AIHW, 2011).

In Western Australia a random sample of non-Indigenous women were invited to participate in a survey on maternal alcohol consumption. Eighty percent (80%) reported drinking in the three months prior to pregnancy, and 59% per cent stated they drank during at least one of their trimesters. Within this same cohort 15% drank in excess of the current Australian guidelines during the first trimester, as did 10% in the second and third trimesters (Colvin et al., 2007).

6.8. Conclusion

FASD is clearly not an Indigenous specific problem although FASD affects Indigenous communities and culture. It is possible that FASD is more easily recognised in Indigenous populations than in some non-Indigenous populations due to the intensity of occurrence in some communities, whereas the occurrence of FASD may be more dispersed across larger populations. Further, the introduction of the Alcohol Management Plans placed a focus has brought FASD into the spotlight in some Indigenous communities.

The prevention of FASD would make an important contribution to improved mental health in childhood, including in intellectual disability, cognitive impairment, learning difficulties, speech and language delay, and behavioural and emotional problems.

7. Explanatory Models of Aboriginal Alcohol Use

7.1. Introduction

Alcohol use in Aboriginal communities is recognized as a social problem. The effects of alcohol overuse in the individual person is perceived in terms of illness whilst the cause of this illness or disease is social. Yet the effect is still viewed from the vantage point of the medical model.

Morgan (1996) states:

> *The term medical model primarily refers to a biological view of illness, upholding physical causes as the factors that give rise to the disease process. In terms of the approach to treatment of health problems, the medical model is the one with the longest historical tradition and is predominantly the one used again today against all other theories are measured.*

This understanding has been supported by Polgar and Thomas (1995) who state that;

> *In western society the medical model has been and will continue to be an influential model for guiding clinical practice and health research. The role of the health professional according to this model is to identify the location and cause of the problem and to implement appropriate measures to correct the problem.*

Lupton (1994) suggests that*:* "in the functionalist view, illness is considered an unnatural state of the human body causing both physical and social dysfunction, and therefore a state which must be alleviated as soon as possible". The patient usually has a passive role in this procedure and is seen to comply with the health professionals' recommendations. In the context of the medical model the most appropriate research is seen as that which improves the technical effectiveness and therefore, the social power of the health professional (Polgar and Thomas, 1995).

Many studies utilising a medical model to ascertain information about alcohol use among Aboriginal people rely on a pathological approach. The overuse of alcohol is identified as a disease, one that can be diagnosed and treated. Once the causal pathways are sought and identified, it is expected that elimination is possible.

By way of example, Yellowlees and Kaushik (1992) carried out studies in Broken Hill that attempted to describe psychiatric disorders seen in patients presenting for treatment in a rural area. The patients were seen primarily in the community, in both public and private practice but also in the local base hospital and prison. Seven hundred and seven patients were examined and compared with a national study identifying similar disorders. The results of the study were compared to previous studies conducted in Australia during the same time-frame that identified specific disorders that were more prevalent in rural areas. Yellowlees and Kaushik (1992) suggest that re-occurring life problems including domestic violence, sexual assault, and incest are commonly identified in women referred for psychiatric assessment.

7.2. Beyond the medical model

Hunter (1993a) attempts to define a psycho-social approach to Aboriginal alcohol use that goes beyond the individualised pathological view of the medical model as is evident in manuals such as the Diagnostic Statistical Manual for Mental Health (Version IV). While the 'medical model' views alcohol misuse as a medical disorder that has a biological basis, possibly stemming from a genetic susceptibility, the psycho-social model and the social inter-actionists challenge the disease model approach by believing that alcohol misuse is a learned behaviour as a direct experience with the external environment. As Hunter (1993a) and others postulate that drinking has become patterned behaviour linked to particular positive values that were or are regarded by many Aboriginal people as being desirable and part of an expressed way of life.

Indigenous people have made claims that alcohol misuse and ill health are a direct result of the oppression inflicted upon them by colonists, the loss of culture and spiritual roots and being denied their way of life (Sumner, 1995). Brady (1995) suggests that the evaluation of treatment of alcohol misuse by

broader community members is inundated by poor methodologies, therefore, when treatment programs include traditional healing, Aboriginal people must be allowed to re-connect with their culture and spiritual roots to ensure the success of intervention and recovery within treatment programs.

7.3. Developmental psychology

Broader psychosocial models used to explain drinking in Aboriginal communities take into account the cultural environment in which the individual develops and learns how to respond, react and behave. There is an ongoing debate among theorists as to what extent drinking can be said to stem from natural causes, such as genetics, for example, and to what extent drinking is purely learned behaviour.

The terms nature and nurture apply to what is learned and what is innately determined. Psychologists approach these questions in different ways. One way is through exploring how individuals make assessments of their needs, and meeting them, advocated by Inhelder and Piaget (1958), and the other is a psycho-social approach that assesses how people see themselves in relation to their social and cultural environment, and how they assess their need in those terms, as put forward by Erickson (1959). This suggests the importance of studying child development in different cultural contexts. Helman (1994) stated that: “one focus in anthropology is the study of enculturation, the process whereby a growing child acquires familiarity with his culture.”

Helman’s suggestion leads the way to cross-cultural rearing practices where the variation of child rearing practices is clearly distinctive in different parts of the world and how these various practices prepare the children to become complete and different kinds of adults, this being seen as a way of life of a group of people.

Annette Hamilton (1981) in her work carried out among the Angarra in Central Australia explores the processes of child development in this cultural context and compares these to the psychological development models of Piaget. Hamilton (1981) proposes that:

In Piagetian thought development changes from birth to maturity constituted a fixed sequence of stages, each characterised by a particular organisation of structures and affected by continuous interaction with the environment. The character and variety of environmental stimulation are of prime importance, since the young and growing infant can respond only to variations in his environment, it must provide adequate experiences for him to cope with.

Hamilton (1981) further suggests that as a result of investigations undertaken during the 1960's, cultural factors must be of great importance in the unfolding of mental sequences. These investigations indicated that what:

Piaget saw as the normal course of mental development and intellectual organisation in children is strongly affected by their cultural environment and that not all environments provide the same sorts of stimulus and hence do not foster development of the same mental process.

7.4. Culture and personality

When considering culture and personality, one is concerned with the ways which the culture as a society influences the person who grows up within it. This approach is supported by Keesing (1981) who stresses: 'cultures comprise of systems of shared ideas, systems of concepts, and rules and meanings that underlie and are experienced in the ways that human beings live'.

Culture can then be seen as a set of guidelines, both explicit and implicit, which will provide the individual with a tool for transmitting these guidelines onto the next generation. Growing up in any society is a form of enculturation, whereby the individual acquires the cultural vision of that society. The culture of one's society provides a number of pre-determined responses to life's questions. As a child grows, he or she will eventually see the world through the specific eyes of his or her culture. Their perception of their identified culture provides them with a tool for coping with daily life. When one has mastered these methods one's sense of confidence increases.

Cultural constructionism is one perspective that explains cultural differences in terms of these collective cultural understandings, rather than understanding differences in terms of the individual. According to cultural constructionists, there is no sense in which the self exists outside the influence of the world in which he or she finds the self. Individuals are always born into a position in a kinship system and a place in the world. The way we learn to think about ourselves and others stems from the influences of this position and place. Self does not exist in any sense outside of the cultural context in which we are born (Lupton, 1994).

It is believed that the cultural world or environment one grows up in will "shape" the specific manner in which one expresses his or her feelings. McConnell (1986) also states that "early social contact with adults serves to teach children cultural rules, gender-related rules and personal rules involving emotional reactions." This position integrates the roles of nature and culture in individual development.

7.5. The life-cycle model

One of the most commonly utilised psycho-social models in contemporary writing is the life-cycle model developed by Eric Erickson. Erickson placed the developing individual within a cultural context that both affected the individual's development and was affected by it.

Erickson and Erickson (1997) describe human development in terms of eight stages, the first five spanning infancy, childhood and adolescence, the last three stages of adulthood. Erickson and Erickson (1997) felt that development involves resolving important conflicts by acquiring new competencies. If the child is to successfully resolve this conflict and develop a sense of autonomy, it is important that its parents encourage attempts to explore and provide opportunities for independence. Erickson (1959) also suggests that once children have reached the age of four or five they resolve the crisis of autonomy by developing a sense of self through identification with parents and a sense of responsibility for one's actions. Erickson and Erickson (1997) feel that, "successful resolution of this stage's struggle relies to a large extent on the responses of their peers and their care givers, especially schools and teachers, to the child's efforts." At this stage, praise and recognition are important when developing

one's self worth. If the child's efforts are not rewarded or seldom praised, the outcome for the child may be that of a lasting sense of inferiority (Lefrancois, 1990).

Erickson's fifth development stage refers to adolescence and involves the development of a sense of identity (Erickson and Erickson, 1997). During the formation of one's identity, one strives for the notion of not who one is, but what one can be. This can be achieved through the interaction with peers, role models, and social pressure. Erickson extends the traditional approach to development by not ending with adolescence but by continuing his description of change over the entire lifespan. He identifies three psychosocial conflicts during adulthood, *intimacy and solidarity versus isolation, generativity versus self-absorption, and integrity versus despair.* The first of these relates to the need to develop intimate relationships and refers particularly to marital and parent roles. The third relates to the realisation that out of life we face death.

7.6. Alcohol and the life-cycle approach

During 1997, as an undergraduate student with the University of Queensland I approached an Aboriginal Community in Cape York Peninsular (Hope Vale) regarding their interest in having a student undertake research relating to alcohol and pregnancy. Ethics was approved through the Hope Vale Council, Apunipima Cape York Health Council and Queensland Health, as my clinical supervisor was an Aboriginal Health Worker in the Hope Vale clinic. The study was a Participatory Action Research approach to gain an understanding of the participants' knowledge, attitudes and perceptions of alcohol and pregnancy. The responses from community participants led to the analysis of the data collected. From the analysis of data, a design and explanation for the Lifecycle Model was created.

Studies carried out in the interests of public health have tended to concentrate on the physical effects of alcohol on the body and have circumvented the fact that alcohol use plays a pervasive role in the life-cycle of many Aboriginal people. From birth to death, alcohol use is a familiar characteristic of the environment. The consequences of this are difficult to escape, whether one actually drinks or not.

More than 20 years ago it was first noted that children of alcoholics appeared to be affected by a variety of problems over the course of their life span. It is well noted that

these problems include FAS, which is first manifested throughout embryonic and foetal development, and through to infancy; emotional problems and hyperactivity in childhood; emotional problems and conduct disorders during the adolescent period and of course the development of alcoholism.

After discussions with community elders (1999), I have chosen to identify children who have been exposed prenatally to alcohol and other substances and born into a toxic environment that is awash with alcohol, drugs and violence as Children of Toxicity Syndrome (COTS). These children show signs of co-morbidity where it becomes difficult to specify the precise nature of externalising psychopathology among COTS.

Internalising psychopathology encompasses symptoms such as anxiety and depression with externalising psychopathology encompassing "acting out" types of behaviour – characterised by rule breaking, defiance aggression, inattention and impulsivity all corresponding and placed in the category of ADHD, oppositional defiant disorder and conduct disorder.

Hayes (1997) suggests that as a result of the conflict between trust and mistrust, the child develops hope which is the earliest form of faith. If caregivers and parents provide a warm and loving environment and are consistent in satisfying the child's needs, then trust is developed. On the other hand, if the care-giver or parent is inconsistent in satisfying the child's needs, then the child is likely to feel mistrust towards that person. This is supported by Lefrancois (1990):

> *The infant is initially faced with a conflict between mistrust and a world about which little is known and an inclination to develop a trusting attitude towards that world. The most important person in the infant's life at this stage is its primary care-giver, usually the mother. Successful resolution of the conflict between trust and mistrust depends largely on the infant's relationship with this care giver and on the gradual realisation that the world is predictable, safe and loving.*

Children who are continually exposed to examples of negative adult behaviour develop patterns of behaviour for their later life, i.e. children learn to be irresponsible for their own actions as a result of witnessing negative adult behaviour. Paradoxically these

children also develop caring responsibilities for other children, which may eventually lead to damaging the families' abilities and strengths to guide sensible adult behaviours. As a result FAS and FAE become one aspect of what is necessarily a much broader picture. It is only one segment of the big picture.

The life-cycle approach to understanding alcohol use in Aboriginal communities therefore works because it takes into account the various social, historical and cultural factors feeding into the drinking pattern, while at the same time maintaining the importance of individual development. This approach melds the internal self and the external cultural environment in a way that is consistent with the Aboriginal world-view.

The model, represented in a diagram form in Figure 3, is circular in order to depict the cyclical nature of the stages through which individuals progress. It shows how a range of interconnecting factors that feed into the cycle throughout an individual's life. As these factors need to be understood in the context of their relationship toward one another, rather than as isolated variables, it is difficult to describe them textually like a list. Although this life-cycle model draws from the psycho-social model of Erickson (1959), the stages shift somewhat when applied to Aboriginal people living in the Indigenous study communities. The alcohol lifecycle is reproduced over successive generations. The model provides an approach that is holistic and grounded in historical, cultural and economic circumstances.

Figure 3: Generational Alcohol Life-cycle Model

7.7. Conclusion

Drawing on the work of Erickson, I have theorised a framework that illustrates the various interconnecting factors that feed into this cycle of alcohol use throughout one's life and over time, which both feeds into the environment and feeds from the environment. This cycle is reproduced over successive generations resulting in adults who systematically care for others but take little care of themselves.

The next chapter is the beginning of several research projects that form the focus on the impact of alcohol consumption on culture and the lifecycle along with the context of practical issues identified by community members themselves; and present a tentative beginning to the accumulation of reliable data on alcohol use and pregnancy.

PART C: THE RESEARCH STUDIES

8. GROG BABIES: Where Do They Fit in This Alcohol Life Cycle?

8.1. Introduction

The intent of this chapter was to gain an insight into the level of knowledge about the use of alcohol by pregnant women and how both men and women understood the effects of alcohol use on the foetus.

An abridged version of this chapter has been published (Hayes, 2001b).

Figure 4: How much have you had to drink today

This article explores the levels of community knowledge relating to FAS and specifically the attitudes of young women and men towards alcohol and pregnancy in Hope Vale, a remote Queensland Aboriginal community and Brisbane city in South East Queensland. The study explored perceptions of health and the relativity of the reasons why young women drink alcohol during pregnancy. The study population in the remote community and the urban region consisted of twenty (20) young women aged 14-25 and twelve (12) young men aged 14-25.

As such, the aim of the project was to construct a qualitative view of the informant's knowledge, attitudes and perceptions relating to FAS. Moreover, in gauging the level of knowledge about FAS, care was taken not to judge responses in terms of the interviewer's own knowledge of FAS as someone who has studied in this area of health. The informants' responses are authentically presented as an indication of tacit knowledge that could contribute to possible solutions in providing primary health care services.

The data collection demonstrated that while minimal knowledge exists in communities about FAS, there is a general understanding that alcohol consumption can impact negatively on the health of the unborn child. Measuring the levels of knowledge and consciousness of FAS (as a specific concept and medical risk to pregnant women and their unborn children) against what could be termed as a generalist knowledge of the dangers of alcohol consumption while pregnant, became important in defining how knowledge itself can be qualitatively analysed.

This report utilises a narrative format in its display of dialogue, as the author argues that objectivity and distance to what respondents conveyed is not consistent with Aboriginal ways of knowing. Understanding the inter- subjectivity between the author as an Aboriginal woman and the people in this report, made much of what follows possible and therefore should not be excluded just for the sake of upholding the framework provided by sociological research methodologies.

The physical and social consequences of alcohol use and abuse have been at the core of many studies where questions have explored the genetic susceptibility of Aboriginal people, the historical and political conditions leading to high levels of alcohol use by Aboriginal people and the cultural aspects of drinking in the Aboriginal communities. Academics from differing backgrounds such as social scientists, psychologists, anthropologists and medical scientists have all contributed to the big picture on why people drink.

Aboriginal women are vulnerable for many reasons, particularly when their lives and social interaction are bound up with the use of alcohol. For many Aboriginal women, alcohol is a normative part of the life cycle, as is pregnancy. It is therefore integral that the relationship between alcohol use and pregnancy be explored both from the

viewpoint of health but also within the boundaries of a socio-cultural context that this relationship plays in women's lives.

Being impoverished is a major contributor to ill health within the community. Social issues are compounded when younger people drop out of school early for various reasons including racism, inappropriate curriculum, self- esteem, learning difficulties and behavioural problems. They then become bored with their lives, bereft of goals or opportunities. It is an easy next step to using alcohol.

One of the significant findings of the study was the rev- elation that community members, even those working in the health profession, had little or no specific knowledge of FAS and no knowledge generally of the effects of alcohol on the foetus.

People talked significantly more about the relationship between alcohol and pregnancy in terms of the effects on their lives rather than the effects it has on their bodies. Most young women and young men talked openly about the perceived relationship between alcohol and pregnancy, alcohol and drugs, alcohol and crime, violence and abuse, all of which they associated with their families, relationships, friends, and with the environment that surrounds them on a daily basis.

The young people interviewed strongly confirmed their connection with their toxic social environment and were aware of the hardships and disadvantages that confront them daily. The issues they identified were family break- down, disharmony across the community, family and com- munity dysfunction, the burden of alcohol and drugs, teenage pregnancy, peer pressure, violence within the home and community, stresses of unemployment, shame, pain and anger within, the lack of trust and respect from family, friends and peers, the high incidence of rape and sexual abuse generally, as well as the poor opportunities to gain education and training within the community.

People described a life cycle in which both alcohol and pregnancy were a normative part of life. The relationship between alcohol and pregnancy within this life cycle went far deeper and was more complex than the physical effects of either of these issues. Subsequently, an explanatory model that was developed on the basis of Aboriginal life experiences, provides a framework of understanding people's experiences of alcohol use in the community. According to this model, the experience of alcohol is embedded within the life cycle of community members. It is not useful to explore people's

understandings of alcohol, by analysing a single, fragmented portion of time during which alcohol appears to play a part of their lives.

Experiences of alcohol at any specific point in time are embedded in lifelong experiences and experience that spans generations.

The life cycle framework developed is useful as it draws in all the various interconnecting factors and interacting complexities that feed into this cycle throughout one's life and over time, which feeds into the environment, and feeds from the environment.

In analysing the responses, it became evident that people were describing a set of interconnecting factors that might somehow be described in terms of a life cycle model. This model has been represented in a diagram form (Figure 5). The model is circular in order to depict the cyclical nature of the stages through which individuals progress.

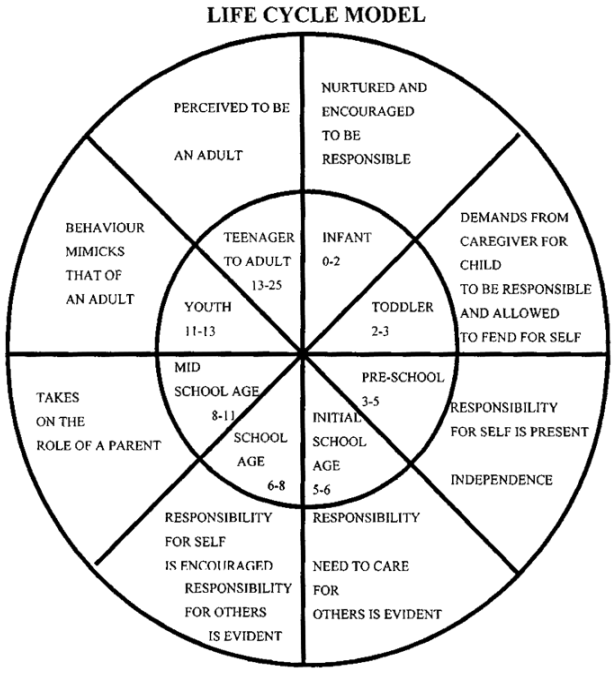


Figure 5: Behaviour at different stages of one's life

The life cycle model begins with the infant being nurtured from an early age (0-2). The parents, who can be seen as the primary source of food, carry out this action. The pool of caregivers, that comprise the extended family, also provide nurturing. As the child reaches the toddler stage in life (2-3), the caregivers place demands on the child to be

more responsible for self-learning and independence. The child is expected and requested to be in control of their feelings and urges. They are encouraged and allowed to fend for themselves and to be responsible for being actively involved with their physical and emotional needs. For example, if a child wants food, they are expected to seek it from whatever sources are available to them.

In the preschool years (3-5), the child's responsibility for self-sufficiency becomes evident and a priority. In the event of a crisis occurring at an early age in one's life, this directs the child to develop a learning for trust and mistrust. McConnell (1986) suggests that as a result of the conflict between trust and mistrust, the child develops hope, which is the earliest form of faith. If caregivers and parents are consistent in satisfying the child's needs, then trust is developed. On the other hand if the caregiver or parent is inconsistent in satisfying the child's needs, then the child is likely to feel mistrust towards that person. The informants' narratives demonstrated that this process was in train.

The following story lines are included to provide examples of how respondents conceptualise their or other's health status in terms of its historical, cultural and systemic impediments.

STORY 1

One participant told a story about his early childhood life, which he felt, was surrounded by alcohol and violence.

> *When one is a tiny little boy and is sent to bed by his mumma who is drinking noisily in the next room where the music is loud, then suddenly, all becomes very quiet and still. You pull the blankets up over your head and lie very still because you become really scared. Too scared to move. You lay there thinking "Is the bogeyman gunna come and get me?" You call out to you mumma and dadda but there is no answer. You suddenly realise that you are all alone in the house. Thoughts wander through your little mind wondering where is mumma and dadda? Where are they? Why don't they hear my call? They must know I am scared? What should I do now? Should I stay here or should I try and run to find my nanna's or aunty's place? It is*

very dark outside. I awake to hear a very loud crash and yelling - people fighting. My uncle then comes in and carries me over to my nanna's house. Here I know that I am safe. There is no reason to be scared anymore.

As the child enters his or her initial school ages (5-6), responsibility has developed for self along with the need to care for others. During the age of (6-8), responsibility is still encouraged for self plus responsibility for others. One can consider that at this stage in the child's life, the child takes on a parental role for all children younger than themselves.

STORY 2

Another participant talked about his childhood experience of the alcohol life cycle.

You go to bed quivering with fear and listening to drunks all night. You wake up and there are drunks everywhere - sleeping all around and some still drinking. You search for food to fill your empty belly before you go to school. Most times there is none. Usually you go to school with an empty belly. You feel tired and you get a pain in your belly from lack of food. You become shy and embarrassed and begin to isolate yourself from others especially those who have food. You run home at lunchtime hoping that there is some food waiting, but there is never any.

When you come home from school there are drunks still there. You go to bed and the drunks are still there - same old cycle. Eventually after being exposed to alcohol year after year you give up and join in - fill your empty belly with grog and become a drunk too.

Figure 6 shows when the drinking behaviour begins. It is not useful to explore people's understanding of alcohol by analysing a single fragmented portion of time during which alcohol appears to play a part of their lives. Drinking behaviour begins at 8 years.

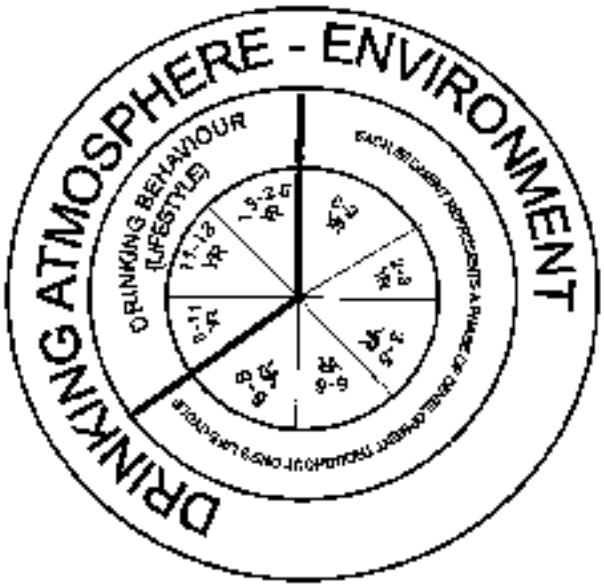


Figure 6: Age when drinking begins 6-8 years of age

Stories 1 and 2 depict the emotions, fear and isolation that a young child can feel when there is a lack of trust in the adults responsible for their well-being. As the child grows older, they begin to realise that his or her survival depends upon their achieving their independence. A lack of respect for oneself and for others can be the result of these emotions.

During the mid-school age stage (8-11), the child learns to take on responsibility for others and often it may be the role of parent to younger siblings and cousins.

By the time the individual reaches the youth stage (11- 13), they begin to mimic the behaviour of adults around them. Then as young teenagers they perceive themselves to be, and may be accepted by the community, as true adults.

Figure 7 shows how a range of interconnecting factors that feed into this cycle throughout an individual's life, both feeding into the environment and feeding from it. As these factors need to be understood in the context of their relationship toward one another, rather than as isolated variables, it is difficult to describe them textually

Figure 7: Reasons for drinking environment (setting), drinking lifestyle (behaviour)

STORY 3

> *She may have been raped. Especially being young girls, they are trying to heal their own problems. So they look for the first person to come along, looking for good faces. They drink beers an' wine, it is cheaper. Except when they really want to party out and look for a man, they get spirits. They get pregnant and then they forget to stop drinking. They have money problems which leads to drinking, which leads to pregnancy, which leads to pension, which leads to drinking, which leads to more problems which leads to more drinking, which leads to more pregnancies - then they can't look after their kids.*

The strategies described in this story are about both dependence and independence. Young women feel isolated and desire to be loved. A man of their own and a baby can provide adult status, along with money gained through either the relationship or through social security payments. If the relationships become violent and the man unsupportive, the drinking resumes and the cycle continues. The dependency of the baby under these circumstances becomes over whelming and burdensome.

STORY 4

I don't think they know if anything can happen to the baby. Something might happen when they drink if they are pregnant. Drinking alcohol is a way for women try to kill their babies. Some young women get drunk and even try to commit suicide, not just because they are pregnant, there is other abuse too. The person drinks alcohol - becoming angry - and then picks a fight with another woman or a man and becomes involved in a fight - killing the baby one time.

The death of the foetus under these circumstances eliminates all responsibility from the mother. Claiming they do not remember, or that it was beyond their control as they were drunk can expunge blame. Both young women and young men felt that the practice of drinking alcohol when you are pregnant is a way to kill the baby. They did not implicate toxic side effects of the alcohol consumed, but rather saw it as a consequence of alcohol consumption.

In story 4 the risks of drinking during pregnancy were well known. It was not the fear of causing FAS or FAE that was of concern to the women involved, rather drinking was seen as a purposeful act in order to initiate a cycle of violence in the hope that is would cause a miscarriage and therefore removing responsibility away from the individual.

A whole range of factors contributed to the cycle described above, exacerbating and creating an inevitability of alcohol as being an accepted way of life and death.

The fear of being alone was all pervasive even within the presence of people. Informants reported their feeling alone as a child even when surrounded by adults drinking and partying. They, the child, felt they were unimportant as an individual, that they were not accepted and that they had been rejected and pushed aside. As the child grew they told of becoming more dependent on friends and peers for acceptance; their behaviours mimicking the adults around them and the peers for whose attention they aspired. Sometimes they reported extraordinary senses of isolation related to what they perceived as the breaking down of their cultural identity as well as the lack

of mutual respect between older and younger community members creating a sense of shame.

A more effective model for health promotion should be aimed towards acknowledging children who are continually exposed to examples of negative adult behaviour. It should be designed around skills which develop positive patterns of behaviour for later life and negating the effects of witnessing irresponsible adult behaviour. Paradoxically, while children develop early caring responsibilities for other children, it may damage the family's abilities and strengths to guide sensible adult behaviours by alleviating adults of their responsibilities.

In conclusion, the research found that the study population did not have any knowledge of FAS, nor were they aware of the extent of alcohol on bodily function and wellness. As previously stated throughout this thesis, maternal alcohol consumption during pregnancy is linked to a range of adverse outcomes for the unborn child. These are included under the umbrella term FASD, a term that reflects the broad range of physical, cognitive, developmental and behavioural effects that prenatal alcohol exposure can have on the developing child (Raymond et al., 2009, Sokol et al., 2003, Riley et al., 2011).

9. The Risks of Maternal Alcohol Use and Child Physical and Psychological Development

Continuing on my journey to understand the link between alcohol and pregnancy outcomes in mothers and their offspring, I as an Aboriginal student undertaking a Masters Degree in Epidemiology was approached to analyse an existing data set relating to pregnant women at the First Clinical Visit and their Last Clinical Visit.

9.1. Introduction

A study was carried out to examine the effect of drinking alcohol during pregnancy on indicators of physical and psychological health in the newborn baby and in children aged 5 years. The study involved 8556 pregnant women attending the Mater Misericordiae Mothers' Hospital between 1981 and 1984 (Keeping et al., 1989). This hospital is one of two major obstetric units in Brisbane, Queensland. Within this hospital there is a public and private section. Women, who choose to attend the public section, are entitled to use the free hospital clinic for antenatal care and have their infants delivered under the supervision of medical staff. This was one of the first such prospective studies to be carried out in Australia linking social and psychological circumstances of the mother to the development of the child over time.

As a consequence of this unified effort, a project was initiated involving interested members from the Department of Obstetrics and Gynaecology, Social and Preventative Medicine, and Anthropology and Sociology. National Health & Medical Research Council (NH&MRC) began funding the study in January 1981, which continued until 1984. The project later received further funding for an extension of the original project to follow up mothers and the children who were five years of age.

When the original data was collected a questionnaire was provided to patients of the Antenatal Clinic at the Mater Hospital at their first clinical visit. This questionnaire contained *Phase 1.A117* (Keeping et al., 1989).

> *This contained a number of scales and questions addressed to the broad areas of marital circumstances, social security benefits, income, housing, employment, education, occupation, migrant*

status, race, religiosity, drug ingestion, anxiety/depression, quality of life, subjective/objective stress, pregnancy attitudes/desires and health habits.

Phase one and two of the questionnaire was delivered between the 3rd an 5th postpartum day. The purpose of phase two was to assess changes that occurred during the pregnancy and also extended into the areas of future family. Phase five was delivered when the child was five years old.

9.2. Literature Review

It is well documented that over-use of alcohol has a significant impact on the health of Indigenous Australians (e.g. (Hunter, 1993b, Reid and Tromp, 1994, Paton, 1995, Australian Council on Alcohol and Other Drugs, 1990). From birth to death, alcohol use plays a pervasive role in the life cycle of many Aboriginal people. The abuse of alcohol is a pervasive and pernicious problem. It is one of the most prevalent psychiatric disorders according to general epidemiological surveys (Helzer and Pryzbeck, 1988).

The consequences of this prevalence are difficult to escape within the context of individual lives. This remains the case whether an individual actually drinks or not. Even the unborn child is affected, as maternal alcohol can cause serious health problems even before birth (Hutchings, 1989). Consequently, from the viewpoint of health, there is a significant risk attached to the relationship between alcohol and pregnancy.

This study aims to investigate this relationship with particular focus on two key sets of variables. The first set relates to the physical and psychological aspects of the newborn in relation to alcohol use during pregnancy and birth-weight. The second set relates to the physical and psychological aspects of the 5 year-old child in relation to internal and external psychological behaviours.

The use of alcohol, tobacco and other drugs during pregnancy continues to be a leading preventable cause of mental, physical and psychological impairment in infants and the older child (May, 1995). Moderate to heavy alcohol consumption by a pregnant woman can result in her child being born with FAS and FAE, which is

considered to be the leading known environmental cause of mental retardation is the Western World (Hayes, 1998).

When maternal drinking is heavy the effects in decreased foetal growth are marked (Little and Wendt, 1991). Lower levels of drinking are also reported to cause significantly lower birth-weights in many studies, with as little as 2 drinks daily being associated with decreased birth-weight (Kuzma and Sokol, 1982, Wright et al., 1983, Streissguth et al., 1984, Little et al., 1986). Some studies have shown no significant difference in birth-weight associated with moderate maternal alcohol use (Davis et al., 1982, Grisso et al., 1984, Suliman et al., 1988).

It is important to note, none the less, that few of the above studies have measured drinking patterns longitudinally, and the period in which the drinking occurs will affect the type and level of growth and development (Streissguth, 1991). Problems with subject recall can hamper attempts to identify how much was drunk and when (Little and Wendt, 1991), and self-reporting of drinking behaviours during pregnancy is also likely to provide an underestimate of the true amounts. As Little and Wendt (1991) point out, *heavy drinking (during pregnancy) is rarely reported*, leaving sample numbers of heavy drinkers small in most studies. Only 63% of patients classified as smokers on the basis of urinary cotinine levels was recorded. It is clear that a dose-response relationship exists between alcohol consumption in the first trimester and spontaneous abortion (Day et al., 1989), as well as morphological problems and low birth-weight (Kline et al., 1980, Little and Wendt, 1991). Drinking in the last trimester appears to affect somatic growth and brain development (Little and Wendt, 1991).

Large prospective epidemiological studies leave no doubt that a significant decrease in infant mental and motor development is associated with maternal alcohol use at even moderate levels (Streissguth et al., 1980, Gusella and Freid, 1984). A study carried out in Seattle found that at 4 years of age, children exposed to alcohol in utero had lower Intelligence Quotient (IQ), poor attention and longer reaction times (Streissguth et al., 1989).

It is also well established that tobacco smoking during pregnancy decreases birth-weight. A review of major epidemiological investigations indicates that birth-weight is decreased by an average of 200 grams by maternal smoking (Young, 1997); a clear

dose response relationship is present, the more the mother smokes, the greater the decrease in birth-weight (McCormick et al., 1990). An Australian longitudinal study on 5342, five year old children whose mothers were recruited early during pregnancy, showed that children of mothers who smoked were more likely to show strong aggressive behaviours (Williams et al., 1998). The confounding effects of smoking are ideally controlled at the design stage of studies investigating alcohol use and pregnancy.

9.3. Aim

To investigate the association between drinking alcohol during pregnancy and the occurrence of physical and psychological problems in the new born baby and the 5 year old child.

9.4. Objectives

1. To describe the drinking habits of the pregnant woman

2. To analyse the association between alcohol use during pregnancy, and the health outcomes in the newborn such as:

- Birthweight
- Apgar scores of the new born
- Prematurity

3. To analyse the association between maternal alcohol use and the outcomes on external and internal psychological behaviours of the child at five years of age.

9.5. Methodology

After initial discussions with various stakeholders, approval was sought and obtained to use an existing data-base, which is a result of a longitudinal study that was conducted by the Department of Obstetrics and Gynaecology at the Mater Misericordiae Mothers'Hospital (Brisbane) and the University of Queensland during 1981 to 1984.

9.5.1. Study Population

The data base contained information about 8556 pregnant women attending the antenatal clinic between 1981 and 1984. Of the 8556 women participating in the study, 362 women were identified as being Aboriginal, Maori or and Islander. This study will analyse the information of 362 women of Indigenous origin.

9.5.2. Study profile

The information contained in the data base were data collected regarding the physical, social and psychological characteristics of the mother at her first clinical visit (FCV), her last clinical visit (LCV), 1 or 2 days post-partum, 6 months after the birth and 5 years after delivery. For the present study the use of data from the FCV, LCV, and 5 years after birth will be examined. At the five-year follow-up of mothers, the retention rate decreased, with 220 of the 362 women being lost to follow-up. Consequently, the final analysis examining the links between anxiety, depression, and maternal alcohol consumption and the effects on the child's behaviour at five years was carried out on the cohort of 142 mothers and children for whom data were complete.

Variables examined in this study were:

1.a. Drinking habits of the mother

Mothers were asked to report on their drinking habit in two different categorical variables "drinking frequency" and "number of drinks each time" (see Appendix 1). These two variables were combined and recorded as a new variable "drinking category" with 4 categories: non-drinker, light drinker, moderate drinker and heavy drinker. Another variable "drinking" was created with only 2 categories non-drinkers and drinkers.

1b. Maternal-smoking

Similarly, mothers were asked to report on their smoking habit in two different categorical variables "smoking frequency" and "number of cigarettes each time" (see Appendix 1). These two variables were combined and recorded as a new variable "smoking" with 2 categories: non-smokers and smokers. This variable was used to identify confounding and effect modification.

2a. Birth weight

Birth weight was recorded as a continuous variable in grams.

2b Low birth weight baby

Babies weighing less than 2500g were identified as low birth weight babies

2c. APGAR Score at 1 min and 5 minutes

Apgar scores at 1 minute and 5 minutes were recorded as continuous variables.

2d. Prematurity (Gestational age)

The weeks of gestation were recorded as a continuous variable in weeks.

3a. Child behavioural problems

Child behavioural problems were measured against an adapted version of the Child Behavioural Check-List (CBCL) (Achenbach and Edelbrock, 1983). The CBCL is a list of behaviours "that caregivers of children are likely to see as being of sufficient concern to warrant consulting a clinician" (Williams et al., 1998). For this survey, 33 of the 113 items were selected from the CBCL. Items were selected for their relevance to the 5-year age category and measured internalising, externalising and SAT (Social, attention, and thought) behavioural aspects. Items on the CBCL describe behavioural procedures; the respondent then grades the behavioural procedures according to three points (often, sometimes, never). The maximum possible score for each of these behavioural issues was 33 points.

3b. Maternal anxiety and depression

The Delusions-Symptoms States Inventory of Bedford and Foulds (1978) was used to measure maternal mental health. This measure has been used extensively and the symptoms listed are not easily confused with those of pregnancy (Williams et al., 1998). This was recorded as a continuous variable. Mothers scoring at or above the 90^{th} percentile were classified as having anxiety or depression.

9.5.3. Statistical analysis

Data were entered into SPSS (version 9) format data base. This same program was used for the analysis. Chi square tests and t-test were used when appropriate. A 95% confidence level was used throughout.

9.6. Results

9.6.1. Drinking Habits of Pregnant Indigenous Women.

At the beginning of the pregnancy in the First Clinical Visit (FCV) of 362 women, 201 (55.5%) stated they did not drink, 83 women (22.9%) stated they were light drinkers, 22 women (5.8%) reported that they were moderate drinkers, 51 (14.1%) women recorded that they were heavy drinkers, whilst 6 women (1.7%) did not respond to the question. At the end of the pregnancy the drinking status was evaluated. Information was missing about the drinking status of 68 of the 362 women at the Last Clinical Visit (LCV). For the women who responded 72.4% (213/294) did not drink, with 4% (12/294) being light drinkers, 10.9% (32/294) were moderate drinkers, and 12.6% (37/294) reported that they were heavy drinkers. Of the 166 women who were non-drinkers at the FCV, 89% remained non-drinkers (148/166), whilst 11% (18/166) became drinkers. Among the 128 women who were drinkers at FCV, 51% (65/128) gave up drinking, and 49% (63/128) continued to drink

9.6.2. Effect of maternal alcohol consumption throughout pregnancy on health indicators in the new born.

9.6.2.1. Effect of alcohol on birth weight

The mean birth-weight of babies born of mothers who drank during pregnancy as recorded in the First Clinical Visit (FCV) was significantly lower than the mean weight of babies of mothers who did not drink (p=0.007) (See Table 3)

Table 3: Effect of alcohol at FCV on baby birth-weight

	N	Mean birth-weight in grams	Std. Deviation	p value*
Nondrinkers	178	3402	571	
Drinkers	136	3223	572	.007

*two tailed t test

Women who drank had nearly two times the risk of having a low birth weight (<2500g) baby (RR=1.73, 95%CI 1.26-2.38, p=0.014 Fisher exact

Table 4: Risk of having a low birth weight baby according to drinking status of the mother during pregnancy

	Drinkers	Non Drinkers
Low birth weight	13	5
No low birth weight	123	172

There was a decrease in birth weight correlating with the amount of alcohol consumed at the First Clinical Visit. It became evident that women who were heavy drinkers gave birth to infants who were lighter in weight, compared to infants born to mothers who were either non-drinkers, light drinkers or moderate drinkers (Table 5).

Table 5: Effect of amount of alcohol consumed at FCV on birth-weight

Drinking category of pregnant mothers at FCV	N	Mean birth-weight in grams	Std. Deviation
Heavy drinkers	46	3088	623
Moderate drinkers	18	3281	616
Light drinkers	72	3296	517
Non drinkers	178	3402	571

Babies' birth weight did not improve significantly if the mother stopped drinking throughout the pregnancy. The mean weight increased from 3157 grams to 3294 grams

(p = 0.148) in babies born of mothers who had stopped drinking during their pregnancy (Table 6).

Table 6: Mean weight of babies according to the drinking habit of the mother at the FCV and LCV

		Drinking at the beginning of pregnancy (FCV)	
		Yes	No
Drinking at the end of pregnancy (LCV)	Yes	3157 n=63	3450 n= 18
	No	3294 n=65	3402 n=148

The effect of smoking as a possible confounder was examined. Smoking during pregnancy was strongly associated with alcohol consumption (Chi square 25.12, $p<0.001$). Smoking was also associated with lower birth babies. Babies born of mothers who smoked had a lower mean birth-weight compared to babies born to mothers who did not smoke (3153 and 3461 grams respectively, $p<0.001$. However, the reduction in mean weight of babies born to mothers who drank could not be explained solely by the smoking habit itself. Stratified analysis revealed that although alcohol did not seem to have any additional effect on the birthweight of babies of smoking mothers, it had an effect on the mean weight of babies of non-smoking mothers (Table 7).

Table 7: Mean birth-weight of babies according to the smoking and drinking habits of the mother.

	Mean birth-weight in grams	
Drinking category of mother	Smokers	Non smokers
Heavy drinker	3067 (n=39)	3204 (n=7)
Moderate drinker	3451 (n=12)	2940 (n=6)
Light drinker	3148 (n=30)	3401 (n=42)
Non drinker	3152 (n=58)	3523 (n=120)

Young age of the mother is a known risk factor for low birth-weight babies. In this study, 119 of the respondents were under 19 years of age. The mean weight of babies in mothers who were under 19 was statistically lower than the mean weight of babies born of older mothers who were 19 or older (3039 grams and 3408 grams respectively, p <0.001). However, the drinking habits of young and older women did not differ (Table 8).

Table 8: Mothers age distribution according to the drinking status

AGE	N	NON DRINKERS	DRINKERS
<19	119	75/119 = 63%	44/119 = 37%
20-24	112	58/112 = 52%	54/112 = 48%
25-27	79	44/99 = 55%	35/79 = 44%
30-34	36	16/36 = 44%	20/36 = 56%
>35	16	8/16 = 50%	8/16 = 50%

9.6.2.2. Effect of alcohol during pregnancy on prematurity

Alcohol consumption during pregnancy did not have a significant effect on the gestational age of babies (p>.0.05, t test when compared to non-drinkers) (Table 9).

Table 9: Mean gestational age according to the drinking habits of the mother

Drinking habit of mother	n	Gestational age in weeks	
		Mean	SD
Heavy drinker	46	38.7	1.59
Moderate drinker	18	38.72	1.49
Light drinker	72	39.1	1.69
Non drinker	178	39.1	1.87

9.6.2.3. Effect of alcohol during pregnancy on APGAR scores

Apgar scores at 1 and 5 minutes were examined, and the results are shown in Table 10. Although the difference was not statistically significant, there was a decrease in APGAR score both at 1 minute and 5 minutes in babies born of heavy drinkers.

Table 10: Mean Apgar scores at 1 and 5 minutes according to the drinking category of the mother.

Drinking habit of the mother	n	Mean APGAR score at 1 minute	Mean APGAR score at 5 minutes
Heavy	46	5.1	6.1
Moderate	18	6.3	6.7
Light	72	6.1	6.9
Non drinker	178	5.9	6.8

9.6.3. Effect of alcohol during pregnancy on child at 5 years

9.6.3.1. Behaviour of child

Three aspects of the child's behaviour were analysed from the data. Externalising, Internalising and Social Attention and Thought (SAT). Each category was measured by giving a score from 0 to 33.

The effect of alcohol during pregnancy on the child's behaviour was examined by comparing these scores according to the drinking status of the mother.

A trend was observed between the amount of alcohol drank during pregnancy and the child's behavioural score for all three categories.

In order to check for the possible confounding effect of the mother's psychological characteristics on the child's behavioural problems, the association between drinking habits, anxiety and depression in the mother was examined, along with the association between anxiety and depression in the mother and the child's behavioural scores.

Table 11: Behaviour scores in the five year old according to the drinking status of the mother during FCV.

		Thought score		Aggression score		Personality score	
Drinking status of the mother	N	Mean	SD	mean	SD	mean	SD
Heavy drinker	17	6.4	2.7	7.8*	2.5	6.1*	2.5
Moderate drinker	7	5.8	1.6	7.4	2.8	5.1	4.0
Light drinker	35	5.1	3.2	5.6	2.8	3.9	3.0
Non drinker	85	5.3	3.3	5.7	3.7	4.0	3.3

*t test , $p<0.05$ when compared to non drinker

No association was found between drinking behaviour in the mother during pregnancy and anxiety levels in the mother when the child is five years of age (Table 12).

Table 12: Drinking behaviour in the mother during pregnancy and anxiety-levels in the mother when the child is five years of age.

	Anxiety in the mother		
Drinking habits of the mother	No of mothers without anxiety	No of mothers with anxiety	% with anxiety
Heavy drinkers	54	3	(5%)
Moderate drinkers	77	6	(7%)
Light drinkers	19	2	(9%)
Non drinkers	181	20	(9%)

Chi square 1.5 ($p = 0.68$)

Similarly, no association was found between drinking behaviour in the mother during pregnancy and depression levels in the mother when the child is five years of age (Table 13).

Table 13: Drinking behaviour in the mother during pregnancy and depression levels in the mother when the child is five years of age.

	Depression in the mother		
Drinking habits of the mother	Mothers without depression n=	Mothers with depression n=	Mothers with depression %
Heavy drinkers	55	2	(3.5%)
Moderate drinkers	19	2	(9.5%)
Light drinkers	81	2	(2.4%)
Non drinkers	195	6	(2.9%)

Chi square 2.81 (p = 0.421)

The association between the mother's psychological characteristics, and the child's behavioural problems at five years of age, was examined. Anxiety and depression were evaluated at two time points: when the baby was three months and when the child was five years old. Mean thought, aggression and personality scores were significantly higher in children of anxious mothers when compared to those of non-anxious mothers. A higher mean score in thought, aggression and personality was also observed in children of mothers suffering depression; however, this difference was not statistically significant (Table 14 and Table 15).

In spite of the strong association between the anxiety in the mother and behavioural problems in the child, alcohol had an independent effect on the child's behavioural problems since when non anxious mothers were examined separately, a significant increase in the behaviour scores was observed in children whose mothers drank during pregnancy. Alcohol, regardless of the amount drunk, did not seem to have a further effect on the elevated behavioural scores of children of anxious mothers (Table 16).

Table 14: The association between the mother's psychological characteristics when the baby is 3 months old and 5 years old and the child's behavioural problems at five years of age were examined.

Anxiety of the mother when the baby is 3mth and 5years old		n	Mean Thought score	Mean Aggression score	Mean personality score
3mths	Yes	19	7.4(p = 0.003)*	7.6(p = 0.03)*	6.1(p=0.007)*
	No	125	5.1	5.8	4.02
5 years	Yes	30	7.2(p = 0.001)*	7.9(p = 0.001)*	5.7(p=0.007)*
	No	114	5.0	5.5	3.9

*p value when compared to non-anxious mothers

Table 15: Association between the mother's psychological characteristics when the baby is 3 months old and 5 years old and the child's behavioural problems at five years of age were examined.

Depression of the mother when the baby is 3mth and 5years old		n	Mean thought score	Mean Aggression score	Mean personality score
3mths	Yes	14	6.9(p>0.05)*	7.2(p>0.05)*	6.2(p=0.02)*
	no	130	5.3	5.9	4.1
5 years	yes	12	7.0 (p>0.05)*	7.1(p>0.05)*	4.7(p>0.05)*
	no	132	5.0	6.0	4.2

*p value when compared with mothers with no depression

Table 16: Effect of alcohol consumption during pregnancy on behavioural scores measured in children of anxious and non- anxious mothers

	Drinking category of the mother	n	Mean thought score	Mean aggression score	Mean personality score
Non-anxious mothers when child is 5 years	Heavy	65	6.3	7.6*	6.0*
	Moderate	30	5.6	6.9	5.2
	Light	5	4.7	5.4	3.9
	Non-drinker	14	4.8	5.1	3.3
Anxious mothers when the child is 5 years	Heavy	20	7.3	8.8	6.3
	Moderate	5	6.5	8.6	3.4
	Light	2	7.4	7.0	5.0
	Non-drinker	3	7.2	8.1	6.3

*p<0.01 when compared to non-drinker

9.6.4. Other health aspects for the 5 year old child

When examining the alcohol consumption of the mother during pregnancy and its effects on other health aspects of the 5 year old child, there was not enough relevant information available.

9.7. Discussion

This study once again reveals the high prevalence of alcohol consumption of Indigenous women during pregnancy.

Nearly half the population of women in the study continued to drink throughout their pregnancy (49%). Although there were women who gave up drinking during their pregnancy, it was noted that there were women who were non-drinkers at the beginning of their pregnancy and began drinking before the end of their pregnancy.

Overall, a dose response effect of alcohol during pregnancy was observed on the birth weight of the baby. Maternal alcohol use has long been associated with low birth

weight in babies. Women who drank heavily had lower birth weight babies compared to the heavier babies born to mothers who did not drink. (Chomitz et al., 1995) note a reduction in birth weight "from 32 to 225 grams (1.1 to 8 ounces for children to women who drank one to three drinks daily. While the effects of heavy alcohol consumption have been well documented; the effects of light to moderate drinking, by the mother, on the foetus have not been thoroughly researched (March of Dimes http://ww/modimes.org).

Results show that the decrease in birth weight did not improve significantly if the mother stopped drinking throughout the pregnancy. Assuming that the first clinical visit occurs during the first trimester it is apparent that it is during this time that alcohol has the greatest negative effect. This result is consistent with the findings of Fournier and Crey (1997).

One of the methodological problems in isolating the effects of alcohol consumption on the unborn foetus and the young child, is the confounding effect of smoking.

Smoking during pregnancy was strongly associated with alcohol consumption and low birth weight babies. Mothers who smoked had lighter babies compared to mothers who did not smoke irrespective of their drinking status. However, it was demonstrated that alcohol had an independent effect on birth weight in non-smoking mothers.

It has been previously documented that children of depressed mothers are more irritable, inconsolable, and at risk of depression themselves (Spinelli, 1998). Consistent with the findings of Spinelli, in this study we found that there was a strong association between the mother's psychological characteristics and the child's behavioural problems.

Although this investigation revealed that children of anxious mothers had elevated behavioural scores and alcohol did not seem to have any further effects on these children, in children from non-anxious mothers we could demonstrate that alcohol consumption during pregnancy was associated with elevated behaviour scores. Therefore, it is clear that alcohol does have a detrimental effect on the child's behaviour.

An interesting outcome was observed, in that no association was found between drinking behaviour in the mother during pregnancy and anxiety levels in the mother when the child was five years of age.

9.8. Limitations of the study

This analysis is limited by the lack of consideration of the nutritional status of the mother during the different stages of her pregnancy. Sayers and Powers (1997) suggest that low birth weight and intrauterine growth retardation could be attributed to maternal malnutrition, which is supported further by a study undertaken by Roberts et al. (1998). It has also been shown that children born to a drinking mother will be more severely damaged as her drinking habits depletes her body of valuable resources that nourish the foetus.

A further limitation exists in that the impact of alcohol consumption by the woman's partner was not considered. A literature search on maternal alcohol consumption showed that the vast majority of studies focus on at least one of the following areas: the consequences of parental drinking (mother and fathers confounded) on the child's development, psychology or behaviour (Barber and Crisp, 1994, Roosa et al., 1996).

Finally, there was a flaw in the questionnaire in that it did not contain ethnic identifiers for Indigenous people. Aboriginal women, Torres Strait Islanders, Maoris and Pacific Islanders were included in the same category. Consequently, it is impossible to discern from the data the true Aboriginal and Torres Strait Islander participants. Cultural and physical differences between Indigenous Australians and others included in this group leads to doubts on the reliability of the data. Poor identification methods were used in the past, with people not reporting their ethnicity but at times research assistants would assume whether one was an Indigenous Australian or not (Brough et al., 2001).

The use of alcohol is particularly difficult to discern through these large population data sets, such as the Mater Hospital Study, as illness associated with alcohol abuse is rarely identified as such. Self-reporting of alcohol use on a lengthy questionnaire is also unlikely to be reliable. Indigenous people are less likely than non-Indigenous Australians to trust the confidentiality claims of any research projects. There are also problems that arise for respondents who distrust the goals of research and the integrity of individual researchers; Aboriginal people are also aware of the impact of stereotypic

views of Aboriginality and are reluctant to participate in research in ways, they expect, may perpetuate these stereotypes. Obtaining information about alcohol consumption from indigenous women using lengthy questionnaires is probably an unsuitable method.

Statistical analysis alone is never going to provide the detail necessary to fully understand the complex cultural, political and spiritual issues involved in describing the link between Aboriginality and the over use of alcohol. There is no opportunity for trust to develop between researcher and participant, and there is no encouragement for participants to engage in deep reflection on the issues.

9.9. Conclusion

Most studies do not differentiate between prenatal, perinatal and postnatal maternal alcohol consumption. Research addressing drinking and drinking problems in mothers has remained a relatively neglected area. I would strongly recommend that further studies addressing maternal alcohol consumption especially during the antenatal period, be undertaken with the understanding that one cannot separate the drinking behaviour from the drinking environment. A holistic approach must be taken that involves treating the person as a whole and not just treating the illness alone. Current information about indigenous mothers is extremely limited. Prevalence rates of alcohol related illnesses indicates that in spite of many programs that tried to address this issue, indigenous women continue to drink during pregnancy (Hayes, 1998, Corti and Ibraham, 1990, The Arc, 1992).

Health promotion and educational materials must be developed which respect indigenous values, and the ways of the people. Research and assessment tools must be culturally appropriate and inclusive of cultural aspects as well as examining the impact on indigenous communities. Programs must be addressed and implemented at a local level and not at a national level.

Specific recommendations where prevention is the initial stage of defence against the effects of alcohol in pregnancy should be implemented. I have suggested that three stages of prevention should be considered when addressing promotion and education for maternal alcohol consumption; these are as follows:

Primary prevention is necessary where actions are taken to prevent the onset of drinking during pregnancy before it happens, in this case informing the community especially young people about the dangers of drinking during pregnancy. Efforts should be aimed at targeting women before and during their reproductive years, as well as their partners, extended family members and community members, especially those individuals who may influence a specific target group of women. Education programs regarding drinking throughout one's pregnancy should be family oriented and culturally appropriate, addressing the knowledge, attitudes and perceptions of the woman, her partner and family, in the context of the community in which they live. This may involve drawing on other existing services within the community that will assist in satisfying the needs for this particular group of women

Secondary prevention is needed to identify those at risk, this can be achieved by screening and providing an early intervention program for women of all ages who are in their reproductive years. Emphasis should be directed towards women who drink or exist in a drinking environment. Information should be provided to all health professionals regarding the risks of alcohol use during pregnancy with the aim of accelerating early recognition of at-risk drinking, and early intervention. Education programs should be designed to provide health professionals with skills that will motivate, encourage and support lifestyle changes for at risk drinkers.

Tertiary prevention attempts to lessen the prevention of the occurrence of FAS or FAE. Specific programs should be designed for children who have been diagnosed with FAS or FAE. Family planning programs should be offered to women and their partners, who are within the at risk category, especially if they already have a child with FAS or FAE.

10. An evaluation of a District Rural Health Service Data Collection on Social Health Risk Factors during pregnancy

10.1. Introduction

Aboriginal people living in Cherbourg identified the overuse of alcohol in their community as a major concern and directly linked it to a large number of health and social problems. The widespread use of alcohol and drug use, among young women, and the links with teenage pregnancy, raised community concerns that the long-term effects of these habits may be having significant impacts on the unborn foetus and the new born infant.

Furthermore, they want birthing facilities to be reinstalled in the community. One of the arguments put forth to the community for not having birthing in Cherbourg, is the assumption of high prevalence of alcohol and drug use by pregnant mothers. Education across all levels of community is therefore an urgent need, as is a good, comprehensive data collection system to measure the actual prevalence of alcohol and drug use by pregnant mothers and to monitor the efficacy of intervention programs.

10.2. What is Surveillance?

Epidemiological surveillance is defined by Gregg (1996) as “the ongoing and systematic collection, analysis, and interpretation of health data in the process of describing and monitoring a health event.” Evaluation of a surveillance system ensures that the needs of the people for whom the activity is carried out are met, and that each activity is of the highest possible standard. An evaluation demonstrates the efficiency and effectiveness of surveillance systems and highlights the response and relevance to community needs. As far as possible the evaluation of surveillance systems should include recommendations for improving quality and efficiency. Most importantly evaluation should assess whether a system is serving a useful public health function and is meeting the proposed objectives. This position is supported by Last (1995) who also suggests that sources of data may relate directly to disease or to factors influencing disease.

10.2.1. History of Surveillance

Public health surveillance dates back to the first recorded epidemic in 3180 B.C. in Egypt. Hippocrates (460 B.C.–370 B.C.) coined the terms endemic and epidemic. John Graunt (1620–1674) introduced systematic data analysis, Samuel Pepys (1633–1703) started epidemic field investigation, William Farr (1807–1883) founded the modern concept of surveillance, John Snow (1813–1858) linked data to intervention, and Alexander Langmuir (1910–1993) gave the first comprehensive definition of surveillance.

10.2.2. Aboriginal health surveillance

As outlined in the Chapter 4, an outcome of the 1967 referendum was the health care of Aboriginal people came under the responsibility of the Commonwealth. The provision of health care services was an addition to the existing services provided by the State Government.

The State administration of a Commonwealth funded Aboriginal Health Program began in the 1970's. The aim was to improve the health status of Aboriginal and Torres Strait Islander peoples through the introduction of health surveillance, public health measures and health education programs, especially in the area of self-help initiatives, with the intent to empower individuals in health care (Department of Health, 1980).

Health surveillance systems became the foundation of health planning, public health programming and evaluation for the dissemination of resources. Consequently, it is integral that surveillance systems are efficient in that they provide only information that is relevant and useful in terms of health planning, and that the information provided is comprehensive and accurate.

10.2.3. Current surveillance system for substance use during pregnancy in Cherbourg

At present the midwife or the women's health worker collects the information regarding substance use during pregnancy as part of the antenatal record chart when pregnant women attend the prenatal clinic. The antenatal record is then attached manually into

the patients' medical records. The medical records are stored in a metal filing compactus within the hospital's medical records section. To date, data has not been previously analysed from these charts, and no reports have been written, disseminated, distributed to the community or to health departments. Below is a flow chart describing the flow of information gathering process.

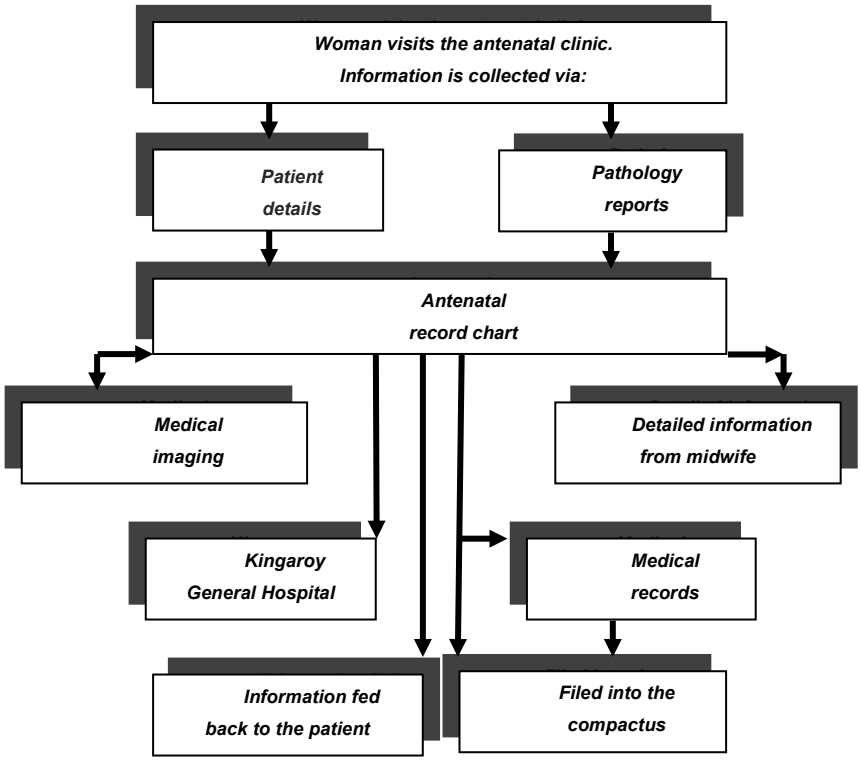


Figure 8: Flow chart of the information collection process

*No computer data base is used to store information collected from the antenatal clinic**.**

10.3. Study method

The aim of this study was to improve the District Rural Health Service Data Collection on social health risk factors such as the use of alcohol, tobacco and other drugs during pregnancy. This was undertaken in three phases.

10.3.1. Phase 1

Medical records of women attending the prenatal clinic from 1st July 1998 to 30th June 1999 were examined and retrospective data was collected. A chart audit was undertaken to determine the extent of data collection in regard to alcohol consumption,

smoking and other drug use as well as other substance use by the women who had attended the antenatal clinic during that period.

10.3.2. Phase 2

Phase two was to design and establish a new social health risk factors history chart to prospectively gather information relating to alcohol, tobacco, marijuana and other substances. Meetings were held with the Cherbourg Health Action Group to discuss the design of a new history chart. Discussions were held with young women who attended the antenatal clinic regarding the design and name of the new history chart. The chart was named the Alcohol, Tobacco and Other Substances data collection record (ATODS Record Chart) (Appendix 1). Interviews were held with the Midwife, Aboriginal Women's Health Worker, and Director of the District Rural Health Service. Discussions were held regarding the characteristics of the data collection system and the use of the information gathered.

10.3.3. Phase 3

The third phase was to evaluate the effectiveness of the ATODS Record Chart in recording useful details of at risk characteristics during pregnancy relating to alcohol, tobacco, marijuana, and other substance use over a twelve-month period. Hospital staff members were informed of the implementation of the new chart and were instructed in its use. Three different midwives were employed at different stages throughout a twelve month prospective period. Conversations were held with each midwife regarding the acceptability and simplicity of the revised questionnaire form. Conversations were also held with the women attending the antenatal clinic.

Women who presented at the antenatal clinic from the 1st July 1999 to the 30th June, 2000 were asked to fill in the revised form with the support of the Aboriginal Women's Health Worker. Information regarding the use of alcohol, tobacco and other drugs and other substance use contained in the revised form was collected from 52 women.

Once the questionnaire was filled out it was added to the antenatal record form and became part of the obstetric history chart. Information gathered from this questionnaire became part of the woman's medical history. These charts would then be accessible

for analysis. The data gathered retrospectively was compared to the data collected during the prospective period from 1st July 1999 to 30th June 2000.

The data collected was entered into a data-base in Excel and was analysed in Excel and SPSS. The percentage of records containing information about each of the different risk factors in the previous data collection system was compared to the percentage of records containing information about each of the different risk factors in the revised data collection system.

10.3.4. Community consultation

The evaluation of District Rural Health Service Data involved accessing medical history files that contained sensitive information. It was essential that community members were satisfied that confidentiality in relation to the information examined was fully maintained. In this case confidentiality was partially ensured by the fact that names of individuals or their specific medical history details were not required. The project was interested only in whether or not questions about a range of risk factors appeared on the questionnaire and if so, to what extent was the recorded information thorough and extensive.

This process of data collection and the aims of the project were made clear to the community members through both formal meetings that were pre-arranged, such as meetings with the Cherbourg Health Action Group, staff from Women's Health and informal discussions with women who attended the antenatal clinic. The discussion process followed the accepted protocols (see Appendix 2) laid down by the Cherbourg Health Action Group, the Cherbourg Community Council and included, community individuals, health workers and women representing the sample group.

Permission to gain access to institutional records was obtained from South Burnett District Manager, Director of the District Rural Health Service in Cherbourg, and women who attended the antenatal clinic. All information was not to be used for any purpose other than that for which permission was obtained.

10.3.5. Community feedback

The results from this study will be presented to the community as a report to the Director of the District Rural Health Service, Director of the South Burnett District Health Service, Women's Health within the District Rural Health Service, Coordinator of the Cherbourg Community Health Service and community members. It is anticipated that a meeting will be held to present the report and its findings to all interested people.

10.4. Results

10.4.1. Phase 1

10.4.1.1. Description of the existing system

The existing data collection tool was identified as being unsuccessful within the antenatal clinic environment at the Cherbourg Hospital.

Women were asked how many grams of alcohol per day they had consumed before they became pregnant and how many grams of alcohol per day they had after they became pregnant. They were also asked if they smoked cigarettes before pregnancy and smoking since pregnant. These questions are located within the Social History Section on the antenatal record form (MR63a). The Social History Box measures 6cm by 6.5 cm. Within this space room is not allocated to write any additional information. One may presume that a tick or a cross is acceptable when answering the questions asked regarding alcohol use.

There was no information about the number of cigarettes consumed or the type of alcohol consumed. Outside of the social history box within the section that identifies information about the present pregnancy there is a line allocated for women to respond to illegal drug use. However, this form does not allow for the recording of detailed information for any of the categories.

The new community designed data collection form (Appendix 1) became part of the women’s antenatal history, the valuable information relating to alcohol, tobacco and other drugs were gathered during the first clinical visit at the antenatal clinic, Cherbourg Hospital.

10.4.1.2. Quantitative results

Forty-six (46) records were examined for the 12 previous months. In relation to cigarette smoking, of the 46 records, there were 24 (52.17%) records without recorded information, 22 (47.9%) charts with recorded information. In the existing system it was unclear whether the information collected was in response to smoking before pregnancy or smoking during pregnancy. The responses were not specifically related to either category whether one smoked before or after pregnancy.

Table 17: Number of charts with recorded responses regarding smoking, drinking and drug history in the existing data collection system

Risk behaviours	**Responses % (n)**	**Non recorded responses % (n)**
Smoking	47.9% (22)	52.1% (24)
Smoking frequency	0%(0)	100%(46)
Smoking quantity	0%(0)	100%(46)
Alcohol	34.78% (16)	65.22% (30)
Alcohol frequency	0%(0)	100%(46)
Alcohol type	0%(0)	100%(46)
Alcohol quantity	0%(0)	100%(46)
Drugs	23.91% (11)	76.09% (35)
Drug type	0% (0)	100%(46)
Drug frequency	0%(0)	100%(46)
Drug quantity	0%(0)	100%(460)
Substance use	0%(0)	100% (46)
Substance Type	0% (0)	100% (0)

10.4.2. Phase 2

10.4.2.1. Midwifes and women's opinion of the system

After consultation the hospital staff claimed that the information collected is not analysed locally, and information is easily accessed in the women's medical records. Conversations were held with the midwives about the acceptability of the existing antenatal record form. The staff felt it was acceptable but in general did not allow for specific questioning about alcohol, tobacco and other drugs. They felt that there was no room for detail and that the women did not understand when asked about grams of alcohol.

Staff agreed that although the form is simple and easy to use it is totally inappropriate, especially in an Indigenous community setting. One staff member felt the form is fine: "the women won't tell you anyway how much alcohol or drugs they use".

To date no alcohol, smoking or drug information that has been collected in the existing form, has been analysed or reported back to the community, nor have specific programs been set in place as a result of this data collection process.

10.4.2.2. Establishment of a revised history chart

After many informal meetings with community members including women, hospital staff, and staff at the Community Health Service a questionnaire was developed specifically to identify the amount, frequency, place and use of alcohol, tobacco and other drugs (Appendix 1).

Discussions were held with young women who attend the antenatal clinic regarding the design of the new ATODS Record Chart. After many efforts in the design stages a questionnaire was developed and approved of by the Cherbourg Health Action Group, Director of the Rural District Health Service, Midwife, and the Women's Health worker.

10.4.3. Phase 3

Women who took part in the study were asked if they had smoked before they became pregnant providing a yes or no response. They were asked how often they smoked

cigarettes during their pregnancy. Information regarding how many cigarettes was used daily, every few days or if they were non-smokers was collected. Women were asked if they smoked 50 or more cigarettes per day, 30 or more per day, 20 or more per day, 1-10 per day or never smoked. Respondents were questioned about whether they felt they were a heavy smoker, a light smoker, a chain smoker or if they had never smoked. Women were asked relevant questions about where they smoked, inside or outside their homes and if any other person smoked inside their homes. They were asked if they would like to quit smoking and if they had tried to give up smoking previously.

The study population was asked if they drank alcohol before they became pregnant. They were asked questions regarding the type of drink they consumed, how much they drank and how often they drank. This line of questioning was followed if they continued to drink throughout their pregnancy. Women were also questioned about drug use before they became pregnant and if they were continuing to use drugs during their stages of pregnancy. They were asked to provide information about the type of drug used before they became pregnant and the type of drug they used during pregnancy. Women were questioned on how they administered the drugs, whether they use joints, bongs, cones, buckets or other ways of administering drugs into their system. They were asked questions relating to frequency of drug use and if they had ever sniffed petrol, glue, paint or other substances (Appendix 1).

The questionnaire was inserted into the existing antenatal record form. Staff, were given instructions regarding the new system. Staff agreed it was appropriate for the women to complete the questionnaire and if necessary the staff on duty would help them.

10.4.3.1. Evaluation of the new data collection instrument

During the 12 months that followed the implementation of the revised chart, 52 women attended the antenatal clinic. The questionnaire was self-administered at the antenatal clinic with the midwives or Aboriginal Health Worker providing assistance to women who were experiencing difficulties in filling out the questionnaire. Twelve months after the implementation of the ATODS Record Chart, all three midwives who had been working during that period in the antenatal clinic felt it was easy to understand and

easily administered. All staff felt that the women didn't have any difficulties filling out the questionnaire. Overall it was felt that there was a positive response from staff and the women attending the antenatal clinic in accepting the revised questionnaire. Although the women who had taken part in the study did feel that the questions were sensitive and intrusive the majority of women who attended the antenatal clinic filled in the form. One participant stated: "yea it's okay to fill out, I understood it. If it's going to help us then we should answer the questions." A response from another young woman stated: "it was fine, I filled it in."

10.4.3.2. Quantitative results

The charts from the 52 women that attended the clinic during that period were examined. The presence of information about the different risk factors was recorded.

Risk factors before pregnancy

When asked if they had smoked cigarettes before pregnancy, only 9.6% (5) of the women did not respond to the question, with 90.4% (47) of women responding (Table 18). As a response to the question about alcohol consumption before they became pregnant, non-recorded respondents totalled 3.8% (2) with 96.15% (50) responding to the question (Table 18). Responding to the question regarding the use of drugs before pregnancy, 7.70% (4) of the women did not respond (Table 18). Responding to the question regarding the use of other substances before pregnancy, 100% responded.

Table 18: Number of charts with recorded responses in the new revised data collection system regarding smoking, drinking, drugs and substance use history before pregnancy

	Recorded Responses	Non Recorded Responses	Unsure Responses
Smoking	90.4% (47)	9.6% (5)	0% (0)
Alcohol	96.15% (50)	3.8% (2)	0% (0)
Drugs	92.3% (48)	7.7% (4)	0% (0)
Substance use	100% (52)	0% (0)	0% (0)

Risk factors during pregnancy

Smoking during pregnancy

When responding to the question relating to smoking during pregnancy, 11.53% (6) of the women did not answer with 3.84% (2) women not responding. Ninety seven percent of the women who said that they smoked during pregnancy responded to the questions about the amount and frequency of cigarette smoking (Table 19).

Table 19: Number of charts with recorded responses in the new revised data collection system regarding smoking during pregnancy

Smoking behaviours	Recorded Responses		Non-Recorded Responses		Unsure Responses	
	n	%	n	%	n	%
Smoking	44/52	84.61	6/52	11.53	2/52	3.84
Smoking frequency	29/30*	96.7	1/30	3.3	0	
Smoking quantity	29/30*	96.7	1/30	3.3	0	

*30 women said that they smoked during pregnancy

Alcohol during pregnancy

When asked if they continue to drink during their pregnancy 92.3%(48) of the study population responded with 7.7% (4) women not responding. All of the women who said that they drank during pregnancy responded to the questions about the amount, frequency and type of alcohol they consumed (Table 20).

Drugs and substance use during pregnancy

As a result of being asked if they use drugs since becoming pregnant 92.3% (48) responded to the question with 7.7% (4) women not responding. All of the women who said that they used during pregnancy responded to the questions about the amount and frequency of drug use during pregnancy. All women responded to the question regarding the use of other substances during pregnancy (Table 21).

Table 20: Number of charts with recorded responses in the new revised data collection system regarding alcohol during pregnancy

	Recorded Responses	%	Non Recorded Responses	%
Drinking	48/52	92.30	4/52	7.7
Drinking frequency	24/24*	100.00		
Alcohol quantity	24/24*	100.00		
Alcohol type	24/24*	100.00		

*24 women said that they drank during pregnancy

Table 21: Number of charts with recorded responses in the new revised data collection system regarding drugs during pregnancy

	Recorded Responses	%	Non Recorded Responses	%
Drugs	48/52	92.30	4/52	7.7
Drugs frequency	10/10*	100		
Drugs quantity	10/10*	100		
Other substances	52/52	100		

*10 women said that they took drugs during pregnancy

10.4.3.3. Comparison of the old and new data collection systems

When comparing the two systems we found a significant increase in the percentage of records containing information recorded about all the risk factors of interest ($p<0.0001$) (Table 22).

Table 22: Difference in response rate regarding smoking, drinking and drug history use during pregnancy before and after the use of the new revised data collection system.

	Before the new system	With the new system	Difference in response rate	P value
Reported on Smoking status	47.9%	84.61%	+36.71%	0.000106
Reported on Alcohol habit	34.78%	92.3%	+57.6%	0.000000
Reported on drug use	29.91%	92.3%	+62.39%	0.000000
Reported on substance use	0%	100%	+ 100%	0.000000

10.5. Conclusion

The existing data collection tool, the Queensland Health antenatal record form (MR63a), was identified as not being effective when used for collecting valuable information relating to alcohol, tobacco and other drugs within the antenatal clinic environment. The new chart trialed in the evaluation showed a significant improvement in that a greater percentage of the charts were completed with details relating to maternal alcohol, tobacco and other-drug use.

There could be several explanations for this improvement. It was identified that the ATODS Record Chart (Appendix 1) was designed in such a way that the language used was easy to understand by Qld Health staff and women from the community. During the design of the new data collection form, after discussions held with the community women, it was decided that the questions used to gather information regarding alcohol had to include glasses of wine, cans of premix drinks or stubbie bottles of beer instead of grams of alcohol. On the other hand, the evaluation itself opened up discussion within the community relating to these issues. It was agreed collectively that this information is important and will be useful in terms of future planning and health promotion.

For this reason, people were more aware of the issue and the processes, and this may have had an impact on both staff attention to this section of the history chart, and to the women's willingness

This raises the question of sustainability once the researcher has left the field and the issue is no longer topical. The chart has been kept simple and short in order to minimise barriers to its completion. Ongoing community feedback on the information gathered and use of this information for the design, implementation and evaluation of programs to decrease these social risk factors during pregnancy will be essential in maintaining the interest of the community on the collection of information.

In addition, the idea of the importance of health surveillance is becoming increasingly important to the community. It is recognised that early identification of health problems be recognised enabling appropriate intervention and better management by the community. The community have a Ten Point Plan (CTTP) for direction to improving health outcomes in Cherbourg. The community as a whole are committed to making evidence based planning decisions in the context of this document (see Appendix 3). The inclusion into the new maternal history chart provides the community with a tool they can use to see their achievements and be encouraged to continue participating in programs that will improve their health.

11. Returning Birthing to the Homeland:

Part I - Risk or Assumption

11.1. Introduction

Pregnant women in Cherbourg receive their antenatal care at the Cherbourg Hospital. During pregnancy, two ultrasounds are carried out at 18 weeks and 32 weeks gestation. These take place at the Kingaroy Hospital. Since 1987, it was common practice that the women of Cherbourg were transferred to Kingaroy hospital during the 37th and the 38th week of the gestational period for delivery of their babies. Provided there are no complications, they are returned to the community approximately 24 hours after the delivery. The Health Centre collects and maintains records of antenatal, obstetric and postnatal history of all women who have given birth to a child in Cherbourg. A paediatrician visits the community at regular intervals, but generally does not see each baby after birth.

The cessation of birthing in the community was due to the unavailability of obstetric qualified medical staff and or midwives (SELLARS, S., personal communication, 2000). This was compounded by an increasing level of birth interventions, and with it, increasing morbidity and mortality rates (WATCHO L., personal communication, 2000).

During 1991, the State Tripartite Forum approached Queensland Health regarding a birthing project for Aboriginal women in remote communities. The Aboriginal Birthing on Homelands initiative commenced in 1991 to address the issue of birthing services on Aboriginal communities. Cherbourg was one of five discrete communities selected to participate within the project. Extensive consultations were held with women from these designated communities namely, Yarrabah, Mornington Island, Doomadgee, Palm Island and Cherbourg (Unpublished, 1998).

As a result of consultations held with women from the communities mentioned above, the reports such as *Some Good Long Talks* (1992) and *Childbirth Business* (1993) became the foundations for the clinical needs assessments and the formation of a

framework for service improvement. The framework was developed to guide plans for improvement of maternal health services in Aboriginal communities: *"Guidelines for clinical needs assessment of maternity health services in Aboriginal communities, delineation of maternal health services in Aboriginal communities and standards for maternal health services in Aboriginal communities"* (Unpublished, 1998).

As a result of the needs assessment it was concluded that a birthing service should be established at Cherbourg and that funding should be provided to the hospital in Cherbourg to build and equip a birthing suite (Unpublished, 1998). While it is important that women who are at high risk of obstetric risk complications receive appropriate care at a larger hospital, it is equally important for women to be able to deliver in a supportive and familiar environment. Accordingly, women's birth risks should be measured rather than assumed. However, Queensland Health maintains the position that birthing cannot take place in Cherbourg due to the concerns relating to high risk factors for Cherbourg mothers and babies.

The argument for returning birthing to the Cherbourg community would be significantly strengthened given community mothers' dissatisfaction with their being transported early to Kingaroy in preparation for giving birth and the growing perception of there being little or no benefit to mothers and babies. Cherbourg mothers would appear to have a strong case if no quantitative evidence to indicate significant risk to mother and baby can be offered.

Discussions were held with the Coordinator of the Cherbourg Community Health Service, the Director of the District Rural Health Service in Cherbourg, Cherbourg Health Rights Action Group, and the District Manager of the South Burnett District Health Service. Further conversations were held with community members, health workers and the staff of the Cherbourg hospital. It was revealed by health workers and community members that Queensland Health maintained the position that birthing could not return to Cherbourg because the risk for Cherbourg mothers and babies was too high. The risk categorisations are not based on empirical evidence, but rather on an assumption about risk for all Aboriginal women (HRAG members, personal communications, 1998).

As a result of discussions held with women and health workers in Cherbourg community, a number of questions emerged concerning the assumption of obstetric risk of pregnant Aboriginal women from Cherbourg. Although this risk is assumed, it is unknown what particular risk factors pregnant Aboriginal women actually experience. The outcomes of their delivery were not revealed to the mother. The risk categorization, it was felt, was not based on empirical evidence, but rather on an assumption about risk for all Aboriginal women.

As an outcome of consultations held with members of the Cherbourg Health Rights Action Group, it was decided that an empirical study was the most appropriate method by which to ascertain actual risk categories for women.

The purpose of this study was to therefore twofold:

(a) measure the level of obstetric risk for women who had been transferred from Cherbourg to Kingaroy during 1995 to 1999, for delivery of their babies and

(b) describe the details of the delivery and the outcomes for mother and child and identify whether the current obstetric risk assessment tools are good predictors of obstetric outcomes.

My role was to support the women of Cherbourg to gain evidence to support their efforts to bring birthing back to Cherbourg.

11.2. Perinatal Records

During the time of the study the attending midwife at the antenatal clinic is responsible for maintaining the records of the progress of the pregnancy on the antenatal record (MR63a), this form has since been updated to be part of the Pregnancy Health Record which is provided to all women who present at the antenatal clinic on their first clinic visit. Each visit is then signed by the midwife. Queensland midwives and/or obstetricians are required by law to complete the Perinatal Data Collection Form (MR63d) (Appendix 4) upon delivery. While there is a tick box provided to ascertain the profession of the “principal accoucheur”, that is, obstetrician, other medical staff, midwife, student midwife, medical student or other; there is no space allocated for either a name or a signature. If abnormalities are detected with the new born infant

then the medical practitioner must complete a Congenital Anomoly Form (MR66) (Appendix 5).

Deficiencies were evident with both the Antenatal Record (MR63a) and the Perinatal Data Collection Form (MR63d). Firstly, few records were adequately completed, especially where antenatal records had no data recorded and instead red lines drawn obliquely with “see previous records”. Further investigations to trace previous records meant that in some cases up to seven years had elapsed without any antenatal recording, even though it was known that the mother had given birth in the interim at Kingaroy Hospital.

In reviewing the Perinatal Data Collection Form (MR63d), emphasis was placed on discerning the mother’s socio-economic level under “class of patient” and “marital status” to the point of asking whether she was single, married or defacto, widowed, divorced, or separated, but other crucial physical birth data of the infant was not requested. For example, space was allocated for the baby’s birth weight but there was no allowance for other important data such as head circumference and length. However, space is allocated on the antenatal record under “postnatal progress” for the infant’s weight and head circumference, but again no requirement to record length.

The weight of a new born without a measure of its length is as crude a summary of its physique as is the weight of a child or adult without a measure of height. The addition of birth length allows the long thin baby to be distinguished from the short fat baby. With the addition of the head circumference the baby whose body is small or stunted in relation to its head, as a result of ‘sparing’ of brain growth can also be distinguished. Thinness, stunting and a small trunk reflect daggering foetal adaptions to under nutrition and other influences.

Barker (1998) identified “long term consequences” as being especially related to early demise from coronary heart disease, hypertension and disturbances of glucose/insulin metabolism. Najman (2006) states that, benefits of perinatal data records cannot be over emphasised.

While socio-economic status is also strongly linked to foetal growth and adult disease in later life (Gillman and Rich-Edwards, 2000). The majority of the population residing in Cherbourg falls in the lower socio-economic bracket. This appears to have

significant relationships to illnesses formerly and wholly attributed to lifestyle. Gillman and Rich-Edwards (2000), when considering these effects, caution “the risks of over-controlling for socio-economic factors existing prenatally, as they may reflect the actual causes of the phenomena”.

It is also noted that Gillman and Rich-Edwards conclude, that there is a need for a “better understanding of how foetal life and postnatal life interact with each other to produce health and disease in adulthood”.

If neonatal measurement requirements are not catered for on Queensland Health’s Obstetric Risk Assessment Forms (see Appendix 6), it will be impossible to evaluate the clinical and public health impact of foetal growth and intrauterine environmental factors to discern connections with adult disease associations. On the Queensland Health’s Obstetric Risk Assessment Form the socio-economic data of the mother also impacted adversely upon allocating a score of one (1) which when added to the total score increased the mother’s categorisation of risk, namely being of high, medium and low risk.

The purpose for collecting such data was to determine whether it is justifiable to routinely transfer women from Cherbourg to Kingaroy for delivery of their babies. The women in the community and the Cherbourg Health Action Group decided it important to measure retrospectively the level of obstetric risk for women who have been transferred from Cherbourg to Kingaroy for delivery of their babies over the past five years; describe the outcomes for the mother and child; and to identify whether the current obstetric risk assessment tools are good predictors of obstetric outcomes and therefore useful for future screening of potential high risk pregnancies.

11.3. Study design

A descriptive cross-sectional study was undertaken involving all women from Cherbourg who gave birth between 1st January 1995 to 31st December 1999, in Kingaroy hospital. A medical record audit was carried out to establish the details of pregnancy, delivery, and post-partum outcomes. A list of all the women who had attended the antenatal clinic in Cherbourg for the five year period was obtained from the hospital midwife. The list was then given to the administration officer at Kingaroy hospital who provided the corresponding medical records. Information was collected

on all birth details including number of pregnancies, live births, miscarriages, deaths and risk assessment. This information was then collated and entered into an excel spread sheet and used to identify whether the birthing outcome placed the mother into a high, medium or low risk category.

11.3.1. Data entry and analysis

Data was entered into Excel spread sheet and analysed using Excel and SPSS. Sensitivity and specificity analysis were performed using Win Episcope. It was expected that the study would result in specific details of the proportion of Cherbourg women displaying certain levels of risk and the proportion of mothers having complications during delivery.

11.3.2. Risk assessment system

An Obstetric Risk Assessment Sheet (A) (Appendix 7) in the format of a questionnaire was designed and adapted utilising the International Obstetric Risk Assessment System (Abraham-Van der Mark, 1993). This assessment sheet also aligns with the Perinatal Data Collection form (MR63D) (Appendix 4) used by Qld Health.

To measure risk factors in women who are birthing, two systems were compared by utilising the Queensland Health Obstetric Risk Scoring Form (QHORSF) and the newly designed Obstetric Risk Assessment Sheet (A). By comparing both systems in areas of sensitivity and specificity, positive and negative predictive values that identified and examined two outcomes; type of delivery (normal vaginal delivery versus any other type of intervention including C-section, forceps, vacuum etc.) and the person performing delivery (midwife versus the doctor). The two different combinations of risk factors were compared by using both the Qld Health Obstetric Risk Scoring Form and the designed Obstetric Risk Assessment Sheet (A). Both forms identified the risk category of 155 women who delivered in Kingaroy hospital, which clearly recognised risk levels in high, medium, low and information missing categories. Understanding the levels of risk measurements were also shown with frequency and percentage. This would to determine which had a better sensitivity and specificity for the two outcomes of interest. In one instance, where the number of responses were low, it was decided after consultation with the Manager of Cherbourg Community Health and the Health

Action Group that the high and medium risks would be combined and in the other medium and low risk were also combined.

The International Obstetric Risk Assessment System had been trialled and proven successful internationally in countries such as Holland (Abraham-Van der Mark, 1993). Women's health was classified into categories receiving an allocation with one or more risk factors, which was then assigned to one of the following groups A, B or C.

11.3.3. Categories of Risk for Midwifery Clients

Categories of risk are subjective and flexible rather than fixed. Different approaches to risk categorisation are appropriate in different contexts. In this light an alternative categorisation to the one used by Qld State Health was examined for its applicability to an Indigenous community setting. Risk assessment had been compared from the two different risk assessment systems.

11.3.4. International Obstetric Risk Assessment Sheet (B)

A committee/group of women including the midwife, medical doctor, women attending the antenatal clinic, classified women with one or more risk factors to one of the following groups:

GROUP A. The woman would receive primary care [from the midwife] and the confinement could take place at home or in the hospital.

GROUP B. The woman would be referred to the obstetrician for consultation. After his or her advice, the midwife and woman would decide on subsequent care. The consultation might then lead to a decision for hospital delivery under the care of a midwife.

GROUP C. The woman would be referred to the obstetrician for secondary care; confinement to take place in the hospital.

Qld Health Obstetric Risk Assessment Form **(Appendix 8)**

Within this form there were different variables where a score of 1-4 was allocated for different categories. The categories were Maternal age; Parity; Social Factors; Past Obstetric Performance; Past or Present Medical History; and Present Pregnancy.

High risk was equal to or greater then 8, medium risk had a rating of 3-7, with low risk scoring 0-2. The form also states that a risk score less than 8 does not indicate an absence of risk (Queensland Government, 2016).

11.3.5. Ethical considerations

It was essential that community members were fully aware of the investigative process and were confident that the likely outcomes of such research would be beneficial and worthy of the intrusion into their private files. It was also essential that community members were satisfied that confidentiality in relation to the information examined, had been fully maintained. For the duration of the study, confidentiality was a priority; using a coding system in place of individual names protecting the identity of the participants involved in the project. Every effort was taken to conceal the identity of participants in all written and verbal reports. Under these conditions, ethical approval was given by the Cherbourg Health Rights Action Group, District Manager, South Burnett District Health, and Queensland Health.

11.4. Results

During the chart audit, 157 charts were examined. It was noted at the time that there were a large number of records missing. These amounted to fifty-five (55) records.

11.4.1. Obstetric risk

Within the study of the 157 charts that were examined, the age distribution ranged from 15-41 years, with the mean age being 23.27 years, with a standard deviation of 5.62.

The percentage of risk was measured by two different scoring systems, one being the Queensland Health Obstetric Risk Scoring Form, and the other The Obstetric Risk Assessment System (A), an adapted version of an international Obstetric Risk Assessment System

According to the international Obstetric Risk Assessment Form (B) 86% of the women were categorised as low risk pregnancies, 2.5% as medium risk and 11.5% as high risk (Table 8.1).

The Queensland Health Obstetric Risk Scoring Form shows that 21% of the women were categorised as low risk pregnancies, 58% as medium risk and 19.7 % as high risk and 1.3% missing (Table 23)

Table 23: Obstetric Risk Category according to the adapted Obstetric Risk Assessment Form (B) and the QLD Health Obstetric Risk Assessment Form

Obstetric Risk Category	Adapted International Obstetric Risk Assessment Form (B)		QLD Health Obstetric Risk Assessment Form	
	Frequency	Percent (%)	Frequency	Percent (%)
Low	135	86	33	21.0
Medium	4	2.5	91	58.0
High	18	11.5	31	19.7
Missing	0	_	2	1.3
Total	157	100.00	157	100.00

11.4.2. Delivery and outcomes for the mother and child

Of the 155 women who delivered their babies in Kingaroy, 127 (82.0%) women had a standard vaginal delivery, 18 (11.60%) women had a caesarean section, 4 (2.6%) had breech births, 5 (3.2%) women were assisted with forceps with 1 (0.6%) woman having a vacuum extraction. There were two records with missing outcome values.

11.4.3. Delivery

Midwives delivered 77% (122) of the births, with doctors delivering 5.7% (9) babies. There were 16.6% (26) records that did not identify who delivered the baby.

11.4.4. Apgar scores

The Apgar Scoring system is used to clinically evaluate the cardiopulmonary system of the newborn. The score is taken at 1 minute after delivery and again at 5 minutes after birth. The majority of infants had an Apgar score falling between the category of 7 and 9 (Table 24).

Table 24: Apgar score at 1 and 5 minutes

Apgar score	Apgar 1 minute		Apgar 5 minutes	
	Frequency	Percent (%)	Frequency	Percent (%)
1	1	0.6	0	0
2	1	0.6	0	0
3	0	0	1	.6
4	0	0	0	0
5	3	1.9	0	0
6	6	3.8	0	0
7	15	9.6	0	0
8	29	18.5	8	5.1
9	68	43.3	66	42.0
10	11	7.0	59	37.6
Missing	23	14.6	23	14.6
Total	157	100	157	100.0

11.4.5. Baby's weight

Of the 157 deliveries, 135 infants weighed above 2500 grams, with 13 babies weighing less than 2500 grams. There were 9 records that did not have the babies' weight recorded.

11.5. Sensitivity and specificity of risk assessment tools

The sensitivity, specificity, positive and negative predictive value of the two pregnancy risk assessment tools (the Queensland Health Obstetric Risk Scoring Form and the adapted version of an International Obstetric Risk Assessment Form (B) were examined with respect to two outcomes: type of delivery (normal vaginal delivery versus any other type of intervention including C-section, forceps, vacuum etc.) and person performing the delivery (midwife or nurse versus doctor).

Overall the adapted version of the International Obstetric Risk Assessment gave better results with a sensitivity of around 76% and a specificity of 93% with respect to complicated delivery, and a sensitivity of 100% and specificity between 93% and 95% with respect to the person assisting in the delivery.

If this screening tool had been used to predict which women would have to be referred to Kingaroy for delivery based on the need of a doctor, between 4.5% and 6% (depending on the grouping of risk categories) would have been sent unnecessarily from the community. It became common practise that no women needing a referral would stay and deliver in Cherbourg. A summary of the results is shown in Table 25.

Table 25: Type of delivery, and who did the delivery according to the two Obstetric Risk Assessment Forms

Type of delivery							
		International Obstetric Risk Assessment Form (B)			QLD Health Obstetric Risk Assessment Form		
Risk Category		Complicated delivery	Normal Delivery	Total	Complicated delivery	Normal Delivery	Total
A	High/Medium	10	8	18	13	88	101
	Low	3	111	114	0	31	31
B	High	10	6	16	4	13	17
	Medium/Low	3	113	116	9	106	115
Person assisting the delivery							
		International Obstetric Risk Assessment Form (B)			QLD Health Obstetric Risk Assessment Form		
Risk Category		Doctor	Midwife or nurse	Total	Doctor	Midwife or nurse	Total
A	High/Medium	9	8	17	9	90	99
	Low	0	114	114	0	32	32
B	High	9	6	15	4	13	17
	Medium Low	0	116	116	5	109	114

Table 26: Summary of results using the two different scoring tools.

Outcome	Score system	Combination*	Sensitivity	Specificity	Positive predictive value	Negative predictive value
Complicated delivery	QLD	A	100	26	12.8	100
	QLD	B	30.7	89.1		
	International	A	76.92	93.2	55.6	97.3
	International	B	76.9	93.3		2.2
Delivered by Doctor	QLD	A	100	26.2	53	100
	QLD	B	44.4	89.3		3.8
	International	A	100	93.4	52.94	100
	International	B	100	95		0

* A= High Medium combined versus Low, B= High versus Medium/Low combined

11.6. Discussion

It is generally accepted that the lower age percentile and the upper age group of women giving birth are at higher risk of obstetric problems than those women in the middle age group. In Australia, the median age of all mothers is 29.5 years. The median age of Aboriginal and Torres Strait Islander mothers across Australia is 24.6 years. In this study the mean age was 23.27years. While this age is lower than that for the Australian population at large, it is not so low as to place women in a risk category (Australian Bureau of Statistics, 1998). For example, teenage births, and particularly young teenage births are commonly regarded as risk groups (Queensland Health, 1997). Age, in itself did not place the women of Cherbourg at significant risk for obstetric problems.

Another commonly considered risk factor for poor obstetric outcome is parity. Generally perinatal statistics tend to indicate that grand multi-parity is associated with

mothers from a remote area, and with Aboriginal mothers from remote areas (Queensland Health, 1997). Nonetheless, the women in Cherbourg are having on average 3 to 4 children. This figure does not qualify as grand parity and so, in itself, does not suggest more than a moderate increase in risk. The majority of deliveries making up this investigation were standard vaginal delivery. Babies were delivered by midwives. This included breech births. It appeared that the caesarean sections were elective. Perinatal statistics suggest that Indigenous mothers are more likely than non-Indigenous mothers to have a spontaneous onset of labour, a vaginal delivery, and an intact perineum (Queensland Health, 1997). This suggestion is born out in this study. Foetal stress, primary postpartum haemorrhage, and retained placenta are more common among Indigenous mothers than non-Indigenous mothers, yet there were very few examples of these in this study. One of the primary characteristics indicating a poor outcome for infants is the measurement of birth-weight. Among the Cherbourg babies included in this study, birth-weights were mostly high. Overall (108) 68.78% babies had high apgar scores and (135) 85.98% had healthy birth-weights >2500 grams.

In every case it was found that the Queensland Health assessment tool showed low sensitivity. The International assessment tool showed high sensitivity and specificity. Consequently, it is clear that the International tool presents a more effective tool for measuring risk of risk potential measurement.

During the year 2000, there were 10,757 nurses in midwifery, with 15 nurses registered in midwifery only (Queensland Nurses Council, Annual Report, 2000). At present there is a country wide shortage of midwives with the mean average ages of midwives in Queensland now being 51 years (HALL, V., personal communications, 2001). The recruitment of medical staff is an ongoing problem. Doctors often without knowledge on Indigenous Health issues and rarely with little or no obstetric experience are being employed in Cherbourg.

11.7. Conclusion

This study aimed to quantify the obstetric risk of pregnant Cherbourg women. Focusing on the risk assessment tool that has the highest sensitivity and specificity, it was found that (111) 86% of women do not have a significantly high risk. On

conclusion it is important to mention the limitations of the study, firstly, data on gestational age was not reported in all charts. This lack of reporting also contributed to limits being placed on the interpretation of birth-weight as an index of foetal growth in this study. More importantly the lack of and/or missing information in the antenatal records was a concern. Secondly the reporting and interpretation of birth-weight in relation to the mother's health status was not consistent, for example, there were many (13) infants born of high birth-weight (>4000 grams), but no evidence that the mother had gestational diabetes. The missing records hindered the study to the degree that a true overall picture could not be taken.

Although the risk is assumed, during this investigation the evidence relating to specific risk factors of the women involved in the study or the details of the outcomes of their deliveries in Kingaroy could not be found.

12. Returning Birthing to the Homeland:

Part II - The Right to Choose

12.1. Introduction

This study differs from the traditional approach in that it draws upon having yarning sessions and long talks with Aboriginal women from Cherbourg community who were transferred to Kingaroy for the delivery of their babies since 1987. It is noted by Fredericks (2007) that when Aboriginal women come together to yarn and are allowed and encouraged to use their words, it is recognised that "more accurately" a process begins**.**

12.2. Study design

Within the qualitative component of this study the practice of triangulation was used in order to ensure a more reliable range of perspectives. Combining talking/story telling circles (focus groups), in-depth interviews, and a structured questionnaire allowed for documentation of the issues from the point of view of the women informants. Personal interviews were held with twenty-one (21) women as well as seven (7) focus group discussions with women of all generations represented.

Study information sheets were made available for all participants. It was explained to the women that they might withdraw from the study at any point in time if they wished. Informed consent was obtained from the participants before interviews took place. Hand written notes proved to be valuable as participants chose not to be sound recorded. The women were assured that confidentiality would be strictly maintained as a key principle of the study.

12.2.1. Indigenous approach

The style of conversation used by Aboriginal women using the Indigenous approach such as yarning and story-telling throughout the information gathering session could thus be said to be 'more accurate' than the traditional approach. In doing so, the advantage of using this approach discovers not only information gathered on maternal

drinking and birthing out of the homeland, but also sanctions the progress of the individual Aboriginal woman's discovery of herself.

12.2.1.1. Interviews

Interviewing began with a semi-structured interview format using a pre-planned interview guide. However, it became clear that the participants wanted to talk openly and freely to tell their stories. Consequently, a two-way communication process between mself as the researcher and the informants began to develop and was not discouraged. Techniques used whilst interviewing included clarifying the question if needed by repeating it again in simpler language, allowing the interviewee time to respond to the questions, and being aware of the tone and speed in which the researcher spoke. These issues were important for a number of reasons. Firstly, the subtle differences of language meant that the participants sometimes needed to reflect on the question before they were comfortable in knowing exactly what was being asked and being mindful that not all participants spoke standard English. More importantly, the position I held as the researcher placed me in a constant state of awareness of the need to demonstrate respect to community members. Speaking in a respectful tone, at an unhurried pace, and waiting respectfully for a response, were appropriate communication styles that yielded forthright and thoughtful responses.

12.2.1.2. Talking or Yarning circles (focus groups)

As the researcher I chose a less formal group interview process, which was held with family members living together, and with members of different groups who attended the antenatal clinic in the Birthing Hut. I found that the strengths of group interviews are that data is produced in a limited time frame and informants were keen to participate. They readily cooperated in identifying beliefs, attitudes, behaviours and opinions from the community. The techniques used were unstructured open-ended interviewing suggested by the following authors (Yoddumnern-Attig et al., 1993).

12.2.1.3. Data analysis

A thematic framework progressed along with the responses that are explained in detail in the results section.

12.3. Results

It became obvious during the interviews that many women had thought carefully about where they would like to have their babies delivered. The pressures associated with the feeling of isolation, leaving the family behind, and the issues dealing with rearing a family, had an important impact on their decision about whether to have their babies delivered in Kingaroy or in Cherbourg.

12.3.1. "This is our Land"

For many women the cultural link associated to land and wanting to give birth on their homeland was especially important in their decision making.

Below are responses by community members: *'We wanna have our kids here'*

A response from one woman was, "*I want my kids to be born in Cherbourg. This is their own land".* Another mother said, *"I was in labour all night, I would have liked to have 'em here cause' this is our land".*

It was emphasised by one person that, *"I would love to have birthing back in Cherbourg. I was born 'ere and I want to have my babies 'ere"*. Another woman respondent agreed saying, *"I would like to have my kids here in Cherbourg too, I was born in the old hospital in Cherbourg and other family were born here"*. This response was also supported by another woman who stated, *"I was born here and want to have my children here. It's a cultural reason. I want the choice to have my baby on Wakka Wakka land".* According to one woman, *"It was a political move to take it away".*

A respondent suggested that having the baby in Cherbourg would instil a sense of ownership and pride especially, *"When the baby grows up, when he is asked, where you from?, he can say Cherbourg, not Kingaroy".*

This sense of pride in being born a Cherbourg baby was supported, *"All the little ones will grow up saying they don't come from here, and I lived in Cherbourg all my life. I want to have my baby here".*

12.3.2. The midwife delivered my baby

Women were aware that the reason for birthing facilities being moved to Kingaroy had to do with reducing risk. They were surprised that even though they travelled to Kingaroy, midwives still delivered their babies, just as would have happened at Cherbourg.

A woman stated, *"I felt safe with the service in Kingaroy, stayed for a couple of days. The midwife delivered my baby".*

All the women were supportive of midwives delivering their babies. *"The midwife delivered in Kingaroy. Why can't they deliver here in Cherbourg?"*

12.3.3. They put a monitor on you and go away, just leave you

Most women felt concerned however about being left alone by the midwives. One woman stated, *"They put a monitor on you and then they go away, they leave the room".*

This was supported by another woman who noted, "*I had a monitor on. The nursing staff they come and go. Would have been better to have them here in Cherbourg".*

One woman said, *"I didn't feel safe. The midwife went for a cuppa. She put the monitor on and just left".*

12.3.3.1. It's Better in Cherbourg

Many women were prepared to make a direct comparison between having their babies at Cherbourg and having them at Kingaroy. One woman said, *"I had my kids in Kingaroy. Would have been better in Cherbourg. Came back to Cherbourg Hospital the next day and stayed in for a week. They have a little nursery, have a humi crib but don't use it".*

Another woman stated, *"I feel safe here in Cherbourg. The staff are different"*. An older woman said, *"I had one here in Cherbourg before birthing was taken away. I was happier here".* An older woman said, *"Some still have'm here eh! They wait until the last minute".*

12.3.3.2. Family can come visit

Women spoke of the isolation they felt when they didn't have contact with their families on a daily basis. They expressed the need to have their partners and family visit during their confinement period. One woman stated, *"It's closer for family to come and see you".*

Another respondent stated, *"Better than going to Kingaroy. You get support here, family can come".* Most respondents said, *"It's too hard for partner to come to Kingaroy".*

12.3.3.3. It's no good going to Kingaroy

Less immediately visible than the removal for birthing, but as equally traumatic, are the feelings of fear, anxiety and isolation. A young woman stated, *"I had a baby in the ward. They wouldn't believe me, baby was in foetal distress. Had pains and they kept getting heavy? They wouldn't believe me. I had him on the bed. I walked out. I was there two days before I had him so they had plenty of time to make sure I was okay".*

Another young woman told of her concerns, *"I remember I had a miscarriage. They left me lying in the hall way for one and a half hours. I was in the outpatients' room and then they took me outside the room and left me".* The response from another participant was, *"They used blunt scissors to cut the cord and also to cut the peritoneum while I was in labour, I felt every bit of it".*

12.3.3.4. Long way to go to Kingaroy

Women talked about the difficulty experienced when travelling to Kingaroy whilst in labour. As a respondent explained, *"I would prefer to deliver in Cherbourg. What if something happens on the way to Kingaroy? It's a long trip especially when you are in labour".*

Another person said, *"You get sick of travelling to Kingaroy, no visitors come".*

A participant said, *"I get sick of going to Kingaroy. The midwife is too strict in Kingaroy".*

Most women felt they, *"Don't have same relationship with the staff in Kingaroy as we do here in Cherbourg".*

Most women felt concerned however about being left alone by the midwives. One woman stated, *"They put a monitor on you and then they go away, they leave the room".*

This was supported by another woman who noted, "*I had a monitor on. The nursing staff they come and go. Would have been better to have them here in Cherbourg".*

One woman said, *"I didn't feel safe. The midwife went for a cuppa. She put the monitor on and just left".*

It was emphasised by one person that, *"I would love to have birthing back in Cherbourg. I was born 'ere and I want to have my babies 'ere"*.

Another woman respondent agreed saying, *"I would like to have my kids here in Cherbourg too, I was born in the old hospital in Cherbourg and other family were born here"*.

This response was also supported by another woman who stated, *"I was born here and want to have my children here. It's a cultural reason. I want the choice to have my baby on Wakka Wakka land".* According to one woman, *"It was a political move to take it away".*

12.4. Discussion

Yarning, discussing and listening to the many stories about the encounters that women have experienced during their birthing away from community have identified the importance of having a connectedness to Cherbourg itself, however, the mothers felt that birthing out of Cherbourg has no cultural value or significance. Due to past and present Government policies along with the classifications of risk to both mother and child, the choice for the women from Cherbourg to deliver in the community has been removed.

It is important to understand the complexities that women face when giving birth especially when the women are required to leave the community. By being absent from Cherbourg during the birthing period can have a significant impact in areas of culture, spirituality, family and community.

Women who have experienced birthing in other hospitals, have raised concerns that clearly identify there are numerous staff who are not practicing cultural safety and lack cultural competence when treating Aboriginal women.

Identifying these issues within the service provided is crucial that all aspects of a woman's rights to birth on country, free from racism and discrimination, having connection to community and family should be recognised and amended for the best experience and health outcomes for the mother and child.

12.5. Conclusion

Mothers reported having positive deliveries and infant outcomes when it became impossible to go to Kingaroy. It became clear that women expressed emotional and psychological benefits in having their babies in Cherbourg.

Connectedness is linked to cultural connection, whilst still requiring strong family and community support, which many women identified in their stories. It became apparent that this can be difficult to maintain due to the anticipated removal from Cherbourg to a tertiary facility. In conclusion, the importance of having connectedness is pertinent to one's identity. It provides strength, resilience, spirituality and a place of belonging, therefore if removal from country is required, this can have cultural implications.

13. Our way of being: Honouring the voices of Aboriginal Women

"Culture is respecting our elders (Grandmothers, aunties, and uncles). Being are our first teachers, they guide our way. They are the foundation of who we are - our family."

13.1. Introduction

Aboriginal people living in Cherbourg have identified the overuse of alcohol in their community as a major concern that it is linked directly to a large number of health and social problems (Community Elder, personal communication, 2000).

As an Aboriginal woman I felt that the process of Yarning was used not only to collect information during the research interview but to establish a relationship with Indigenous participants prior to gathering their stories through storytelling, also known as narrative. Yarning, is an Indigenous cultural form of conversation (Bessarab and Ng'Andu, 2010).

Creating community partnerships with community members who are willing to participate in the definition of the research problem, the interpretation of the data, and the application of the findings may aid in addressing concerns and outcomes as a result from community based participatory action research and observational studies (Leung et al., 2004).

Initially my aim in this research project was to document and analyse the awareness of FAS and FAE among young Aboriginal women and men aged between fourteen and twenty-five years, however, the age group became extended to incorporate the various age ranges of community members. My observations not only included adults, and adolescents but children tended to form an important part of the study group. The research does not attempt to represent a random sample of people living in Cherbourg at the time, nor does it claim generalizability cross other Aboriginal communities.

Community members who participated in the research project talked freely about their perception of alcohol and pregnancy in terms of the effects that the relationship between these has on their lives, rather than the effects it has on their bodies. The relationship between alcohol and pregnancy within this life-cycle went far deeper and was more complex than the physical effects of either of these issues. In analysing the

responses, it became evident that people were describing a set of interconnecting factors that might somehow be described in terms of the life-cycle model. It became evident that people in this study were describing a cycle in which both alcohol and pregnancy were a normative part of life as they saw it.

13.2. Study design

Upon arriving in the community, I devoted a period of time to developing a sense of mutual trust and respect between community members and myself. At the community level, efforts were taken to ensure that the community members were aware of my presence and the nature and implications of the research project were clearly understood by all who were involved. My intentions were made clear so not to ally myself with any single group or individual in the community, and it was also made clear that my role in the community was purely as researcher.

A consultation process was carried out with Cherbourg Community Council, Cherbourg Community Health Centre, Jundah (Women's Group), and the Young Women's Group. Before the commencement of the research project, introductory letters with information regarding the project were sent to the collaborating organisations asking for their support. Before seeking the consent of respondents, information relating to the features of the study was disseminated to community members who showed interest in the research. The information disseminated was presented in a way they would clearly understand.

13.2.1. Interviews

I held interviews with seven women and held two non-focus groups with young men aged between eighteen and thirteen years, and three focus groups with women aged between fifty and sixteen years. In-depth interviews were held with health workers and service providers. The particular issues that were discussed were life histories, drinking histories, sexual and reproductive health histories, responsibilities for self and others, attitudes towards alcohol and pregnancy, knowledge towards alcohol and pregnancy, and the experiences of women who drink alcohol while pregnant.

Respondents were encouraged to talk about the problems which they chose to discuss and in ways they felt were appropriate. For the duration of the study, confidentiality

was a priority; the identity of the participants involved in the project was protected by using a coding system in place of participant's names. Every effort has been taken to conceal the identity of the participants in all written and verbal reports.

13.2.2. Observation

My field work in the community involved varying levels of observation in the environment in which the study respondents belonged. While the group interviews provide data about what people believe, the observation technique can provide information about actual behaviour, which in contrast, granted me the opportunity to fully understand the individual's behaviour. As I sat and observed the activities that were happening around me I proceeded to take hand written notes, taken from my position as onlooker outsider.

Collating information by way of this process involves the use of heavily interpersonal methods e.g. case studies of which become labour intensive. I was very conscious that I was probing into the lives and emotional feelings (relating to alcohol consumption and its relationship to pregnancy) of people that I had not met before. There were individuals who showed interest in the topic and were keen to share with me their past and present life experiences and events, but there were individuals also who in a polite manner were not keen to become involved in the project.

Feedback to informants was a crucial ethical requirement of this study. I therefore, reported findings to the Community Council, Cherbourg Community Health Centre, Jundah and the Young Women's Group.

13.3. Before the Stamping Begins

Many people talked about their concerns regarding the widespread consumption of alcohol among young people. This coupled with teenage pregnancy, left them feeling concerned about the effects of drinking alcohol during pregnancy. Pregnant women drank alcohol. The women made claims that they were giving birth to babies that were getting smaller and smaller, and there were the women who had lost babies.

Obviously many people felt that pregnant women drank alcohol. When asked if they had ever seen a pregnant woman drinking alcohol respondents said: "yeah lots, they

drink all the time." This was supported with another respondent stating: "yeah they all do." A statement by one person was: "they all different, got different attitudes, they probably drink to feel good too you know. A lot of them under stress, they all go up and get drunk, they all hard headed, won't listen to nobody." It was identified by one person that: "they drink lots, they drink to get drunk, everybody does."

When respondents were asked if they drank alcohol when they were pregnant, they thought carefully about their drinking behaviour whilst pregnant, and one replied with: "yeah with the second one I did, I drank right up until I had the baby, I just drank beers." A statement by one woman was: "I was stressed. I drank more and more. I lost a couple of babies."

They are also becoming pregnant at an early age, as one woman said: "You look and watch the ones going to the antenatal clinic and ask yourself how many is drinking or drinks heavily. If you got say 10 attending the clinic 9 are drinkers and that's a low estimate."

One woman felt that: "the young girls they been having babies. Everywhere I look I see someone who is about to go in to have a baby you know," and she agreed that, "you see them in town and you see them out here drinking a lot you know." This was supported by another woman sitting: "I see for myself now, they start drinking at twelve years of age."

A statement by one woman was: "I suppose alcohol might play a role in teenage pregnancy, but I reckon the bigger cause of that here is molesting." According to another woman's views*:* "I think they are being molested at a very young age and by the time they develop maturity it's just an everyday thing for them. This was supported by an older participant's response: "there are a lot of young girls who don't have sex out of love, you know and even a lot of adults. They just have sex for the sake of having sex."

The devastating effects of violence on the individual is specifically linked to drinking behaviours, this is supported by claims from an older woman:

> *I drank more and more and then I started drinking spirits, and then wine. The wine never did me any good, it sort of made me worse*

going with boyfriends, getting bashed. I've been bashed around for too long when I was drinking. It was real hard to give up.

Another woman agreed that: "I got bashed from pillar to post getting bashed up and going to the hospital." One participant claimed, "I found that drinking grog more or less breaks your home up and you hurt the ones you love."

It is a common occurrence to see women or young girls with black eyes and puffed up faces following the brawls on the weekends. There are victims who are hospitalised, some even raped or sexually abused, it's like everything revolves around a lifecycle of using alcohol and drugs.

STORY 1:

Marjorie is twenty-eight years old, she has short black curly hair, her face is marked with scars, her eyes are blacked, and her face is puffed while her body is swollen and bruised as a result of being continually beaten and bashed by her boyfriend following the weekend brawl.

Her eyes have a vacancy and you can feel a sense of deep loss and pain. She sits staring out into the yard, as she speaks, softly spoken in a monotone without emotion.

Marjorie is a mother who drinks alcohol to try and heal the pain and suffering. She explained that her babies were getting smaller and smaller, she drank right up till they were born, spirits, then wine and beers, throughout her pregnancy: my baby he got problems now cause of the grog.

There was concern among respondents about women drinking while pregnant. One young woman explained: "that's another thing besides FAS they are smoking marijuana too you know, right up until they have the baby." One person added: "there are a lot of women here who use drugs when they are pregnant, I suppose alcohol and drugs can affect the breast milk too." Another person agreed that: "they drink all through their pregnancy and use yandi too you know, they got no shame."

It became evident throughout the data that women were drinking alcohol at hazardous and harmful levels, and smoking marijuana on a weekly basis. Most respondents were more concerned about drug use than they were about the alcohol issue. People who participated in the research felt that it was a common occurrence for children to grow up with alcohol and drug dependent adults all around them.

Gender and power relations involved were explicit demarcators of how alcohol was consumed as both an individual and group activity. It was believed by community members that they are weakened by the devastating effects of sexual abuse, violence, suicides and attempted suicides, and family deaths. Many individuals who are traumatised by these events often turn to alcohol and drug abuse. When welfare recipients and workers are paid, it is a common occurrence for drinking and drug parties to take place in the community; this usually happens on the weekend and lasts for several days until all forms of financial assistance has expired. Adults and children alike partake in these drinking and drug parties.

Drinking is carried out in relation to external economic influences in the community. As it was explained by one informant: “yeah they drink every week, mainly Wednesday or Thursday and Fridays, they are the main days. Sometimes they go through to Sunday.” Binge drinking often lasts for several days when people have the money. Many young people felt that those who do drink, drink to get drunk and till the money runs out.

Buying alcohol becomes problematic and appears to place the household budget under extreme pressure, especially when the income relies on Centrelink benefits and/or work for the dole (Community Development Employment Program). When the money runs out there are people who, as one participant stated;

> *They hock in their key cards in at the hock shop in town for $30, they then have to pay daily interest before they can get their card back. You can’t borrow any money without putting your card over. It sometimes costs around $210 with interest to get it back.*

Being influenced and pressured by family members and friends to stay involved in their drinking environment it then becomes evident, as is portrayed in the following story line.

Alcohol thus characterises the lifelong experiences of people in Cherbourg. These experiences are more easily understood when linked to a cyclical framework such as provided by the life-cycle model. An older woman spoke of the link between alcohol and the entire life-cycle.

These kids basically got to raise themselves, the grannies burn out. Some women just keep on having kids, some have seven kids and can't look after them. They keep the money and dump the kids on other unruly family members. It's really sad, especially if the grannies don't care for them. Them mothers drink on the river bank, got to bingo, play cards and neglect the kids. The grandmothers have to look after them. The mothers are not being responsible and you end up with kids having kids. They (mothers) should be encouraged to get off the drugs and grog and be responsible for their kids and stop making excuses for them. These old girls are on their last legs. There is too much abuse here it's inter-generational. Someone's got to do something. (Personal communication)

13.4. Stamping the Story on the Kids - Trust versus Mistrust

Erickson's life cycle model begins with the infant being nurtured from an early age (0-2) (Erickson, 1959). As the infant learns to depend upon the parents for sustenance and emotional nurturance; a sense of trust and faith builds. If the infant does not experience the comfort and care of nurturing parents, a sense of mistrust develops which can affect later development.

This nurturing stage is consistent with the experience of Aboriginal children in Cherbourg. If the caregivers and parents are consistent in satisfying the child's needs, then trust is developed. On the other hand, if the caregiver or parent is inconsistent in satisfying the child's needs, then the child is likely to feel mistrust towards that person. In Cherbourg nurturing is carried out by the parents who can be seen as the primary source of food, but in addition, a pool of care givers representing the extended family, including other children, provide nurturing.

Tiny babies are doted on by mothers, fathers, grandmothers and the extended family, especially other small children. Problems arise though, as the infant gets older and requires more attention, by this stage the father has lost interest or has been banished by the younger mother because of his lack of attention. He may be seeing another young woman which causes immense conflict, and may cause the mother to put the

infant aside while she pursues some social life which is likely to include the use of alcohol and drugs.

After being involved in the social scene again, the mother begins searching for love, affection, and attention and may find herself in a position where the inevitable outcome is another pregnancy. If grandmothers or aunties can't cope with the small one, the older brothers, sisters and cousins assume the status of mother.

STORY 2:

It is nearing six-thirty in the evening on Thursday. As Tritt got out of the car he noticed that the grass was longer than when he last visited his cousin Travis. As he approached the house he tripped over one of the kid's bikes that had been left on the path. Tritt automatically went into a jive walk as the reggae music was blearing loudly, he walked in through the garage and around the back of the house. There were two tables set up with the odd chair or two scattered nearby. The tables were covered with a plastic table cover which was patterned in bright yellow flowers against a dark blue background. The tables were laden with chips, nuts, lollies, and left over food from a barbeque.

As Tritt came into the view of the kids who were running around, they let out a squeal, Tritt, Tritt, and ran up to him grabbing his hands. One small boy attempted to jump on Tritt in excitement. Tritt notices that a group of young children were sitting in circle playing cards, and that there were three babies there in prams not far from the fire where the men were standing. Tritt walked up to the men who were standing around a fire which was semi-enclosed in an open cut forty-four gallon drum.

As the evening wore on it began to get cool, but not cold. Kids had blankets wrapped around their shoulders. Tritt noticed one of the babies in a pram had a terry towelling jumpsuit on, which was worn and thin. One man put his stubbie of beer up to one of the babies' mouth and gave the baby a sip of alcohol. A woman said, stop it. "Don't give that baby grog".

As the night grew later, the sound of music became background noise as voices at the party grew louder. People were calling out to one another, some happy, some beginning to grow anxious- past conflicts began to surface. The babies began to become distressed and could not settle.

It was getting colder and they were tired and hungry. The older kids had wandered off away from where the adults were drinking. Women became anxious and angry at the men folk who were appearing to having a good time. The women, anxious to join the men, began giving the babies sips of alcohol to settle them down; this was continually done throughout the night. When the babies continued to cry, the men who were smoking yandy (marijuana) began to blow the smoke into the babies' faces and the people near began to laugh. This party would go long into the night and would probably continue all weekend.

Fear and isolation mark the earliest experiences that a young child can feel when there is a lack of trust in the adults responsible for his or her being. As the child grows older, he or she begins to realise that survival depends upon independence. A lack of respect for their self and for others can be the result of these emotions.

13.5. Testing the waters of Independence - Autonomy versus Shame and Doubt

Between the ages of two and three, Erickson (1959) claims that the infant acquires a sense of control over his or her behaviour, with the realisation that their intentions can be acted out. In Cherbourg, as the child reaches the toddler stage in life (2-3 years), demands from the care givers requesting that the child become more responsible for self-learning and independence becomes evident.

The children are encouraged and allowed to fend for themselves, and to be responsible for being actively involved with their physical and emotional needs. This absence of parental expectations eventually places the child in a position where they learn to be irresponsible in terms of their own safety and well-being, surprisingly though they develop caring responsibilities for other children in their immediate environment.

As previously mentioned most respondents agreed that when a child is two to three years old, they are allowed to fend for themselves and to be responsible for themselves, one person said, “yeah of course they do”, another said, “they have to do things for themselves”.

One woman said: “you see them kids walking all over the community. They know how to cross the road and look after their little friends you know. They think they are all grown up.” Another person felt: “they look after their little brothers and sisters and their friends, sometimes they got nobody around to look after them, ‘cause they are all drunk or yarndied up. They are responsible for their own feed, they know what they want. They’re not safe you know.”

In observation, it was noticed that, there seems to be a sub-culture or groups of little gangs roaming around meeting up with other little kids. The majority of these children have displayed actions of responsibility and caring for each other and younger members of the group, such as making sure they cross the road safely and not allow

them to run away from the larger group or to stay with the other child if there is only two kids in the group, sharing their buys from the shop i.e. chips and drinks or lollies (HAYES, L.G., field notes, 3rd, 4th, 5th, 20th and 21st August 1998).

STORY 3:

Alma is four years old, her bones are small and she has a pretty face with large almond shaped brown eyes. Her hair like soft velvet, is also long lank, and thin tangled across her forehead. Her frailty is deceptive; she can run faster than any other kids, even those who are bigger than her.

Alma takes care of her little sister two and a half, her cousin who is eighteen months old and another child, a little boy about three.

Alma walked down into Wakka Wakka park, pushing her young family members in a pram with the little boy of three running beside her.

Alma struggled trying to balance the pram on the pathway. It is too heavy for her to steer, and keeps falling over the edge of the gutter.

When they reached the park, Alma struggled once again, to try and lift her eighteen month old cousin out of the pram. In the meantime her sister and the three year old boy began to play on the swings.

Alma and her small band of children met up with another band who were also playing on the swings.

Little children as young as two, three, four and five years old organise themselves into gangs or bands to comfort each other. This may very well be seen as a substitute family.

One concerned participant felt:

> *We see a lot of that, the parents, like they send the little toddlers down into the park here pushing their younger brothers and sisters around. These kids are three and four-year old, with younger babies in the strollers and we've had to help the kids push the prams back up so they can head home, while the mothers are sitting at home playing cards or whatever doing their own thing. You know you'll see other kids who are in the park well they'll help look after them and each other to, they show responsibility for each other.*

Within the community, children themselves are taking on the responsibility of their parents at a very young age, helping out their own parents, and caring for siblings.

When children grow up in an environment that is engulfed by alcohol and drugs, they may themselves become involved with alcohol and drugs. One respondent claims: “people are not stable here, especially in the home. All they got is alcohol and yarndi. They got nothing to come home from school to so they get up to mischief and drink grog and smoke yarndi.”

One respondent explained this cycle as;

> *The men here mainly have something to do, well they have their football. They love their sport here but then you got them drinking at the football too. You get a lot of players too here and they see their parents drinking. I seen it all the time and then the kids are copying the parents.*

Some children are exposed to an excess of negative adult behaviours which are easily copied, a natural act for young ones as they grow towards adulthood. In the context of a party where alcohol is being consumed, the child may feel that as an individual they do not matter, they are not being accepted, and they have been rejected or pushed aside. Young children may experience feelings of aloneness and isolation, to solve this, attempts to engage in adult activities, such as taking sips of alcohol while the adults attention is elsewhere is a routine practice.

One person felt that: “there has been a lot of drinking you know. My opinion it starts from the home, that’s where I think it comes from.” As one respondent pointed out: “The kids copy the adults. It all starts in the home. It was hard to get grog when I was young, we had to get adults to get it.”

Study respondents emphasised that: “women were drinking a great deal, often at parties or special occasions, but also as part of a general lifestyle where they drink on a daily or weekly basis.” Most respondents spoke in terms of the sad effects of too much alcohol or drug use to describe the extent of drinking. As one person said: “the children need someone to care for them especially when all the bigger kids are drunk, the parents drunk.”

As the child grows they may depend upon friends and peers for acceptance, love, attention and nurturing. Their behaviours may both mimic the adults around them and the peers that they hope to be with.

It is possible to feel an extraordinary sense of isolation as cultural identity breaks down, there is a lack of mutual respect between older and younger community members and a resulting sense of shame.

These children learn from one another about the boundaries of social interaction within the framework of their play, acting the roles of adults. The earliest sensations of the consequences of one's actions are learned within this environment.

13.6. The Disappearing Childhood and the Pain of Abandonment - Initiative versus Guilt

Erickson[4] states that children between the ages of three and four begin to face the tension between their inner desires and what society expects of them. For Cherbourg children, these years (3-4 years) are characterised by a growing responsibility for themselves and others. The need to become independent and to take care of oneself is a priority, as they have been emotionally abandoned by their carers. Beforehand these children mimic adults unconsciously but at this stage they are quite aware of actively interacting in this role. At three and four years of age, children are expected to take on responsibility, not only for themselves, but for other infants as well.

An older woman claimed that: "when a child goes to school they are responsible for their siblings and friends, they think they are all grown up, they are always looking after someone."

Their faith in the essential reliability of adults does not develop. It is possible to feel an extraordinary sense of isolation as cultural identity breaks down. There is a lack of mutual respect between older and younger community members, and a resulting sense of shame. What society expects of these children, is that they will not interfere with adult activities. Initiative and guilt are emotions that are tied, in the Cherbourg context, to very real life and death responsibilities of survival, even for these children of three and four years of age.

STORY 4:

Mikey, Joyce, Darrell, John, and Polly are small children aged between three and five years old. They are small in build, and all appear underweight for their ages. They sit in a small circle pretending to be drunk having a grog party. The sticks hanging out of their mouths represent marijuana joints and or cigarettes. They have gamin (pretend) rum and coke, beers, and wines.

Mickey and John stand up and shape up to each other re-enacting a fight they saw at home.

Darrell and Polling begin to shove and pull each other. They are all using bad language and swearing at each other during their re-enactment. This is all pretend, but this is how they spend their time playing. This is their interpretation of their reality.

Will their environment, awash with alcohol and drugs claim these children to be children of the grog?

13.7. Walk your Talk - Industry versus Inferiority

In the Erickson (1959) model as the child enters his or her initial school age years (5-6), responsibility has fully developed for self along with the need to care for others.

During this stage of their lives, the children in Cherbourg appear to have developed a sense of responsibility for themselves, developed through the need to care for other siblings which in turn, will become a catalyst for further pain. It becomes clear that the caring and nurturing process is a way of fulfilling their own needs, especially when they are craving for love, and affection, which their own parents or care-givers fail to provide.

An older woman claimed that: “when a child goes to school they are responsible for their siblings and friends; they think they are all grown up. They are always looking after someone.” This was supported by: “yeah they act like they are the parents, they think they are the bosses, boss’in the other kids around making them do things. They look after the little brothers and sisters.”

Some children end up in a position where: “*they parent the parents on a regular basis either weekly or fortnightly.”*

Parents were too often seen by participants to be shirking their responsibilities toward their children. Participants felt *that:*

The parents focus too often remained on themselves, through drinking, drug use and gambling, while children remain neglected and or abused, the parents are not caring or they are too busy with their gambling or bingo playing, their drinking alcohol, yarndi smoking or whatever. They are forgetting about the care of the kids.

One respondent believed that:

While parents may not be directly to blame, it is circumstances of family breakdown that lead to the problems, with immature relationships filling the gaps in caring. If it's a family breakdown and the younger girl hasn't got that support system, he is all she has. He is the only support system she is getting whether she gets bashed, raped or not. They then deliberately fall pregnant so that they have got someone to love and someone who needs them. Somewhere along the line it breaks down anyway because they get sick of each other because they are so young. They don't have the support system there to keep it going, they don't have parenting skills or anyone to teach them. They are too young to be dealing with babies at that age anyway. It is sort of like babies caring for babies - somebody's gotta.

13.8. Resentment - Industry versus Identity Diffusion

Erickson and Erickson (1997) points out that through interaction with one's peers, a sense for self-worth will develop. During the age of 6-8 years, responsibility is expected to have fully developed and it is expected that children will competently care for both themselves, their siblings and other children younger than themselves. In addition, for Erickson, industry and effort at school bring rewards to these children, self-worth develops as children discover they are good at certain things and that society values some skills over other skills.

In the study community, many children tend not to go to school, rather staying at home to take on the responsibility of the household tasks and the role of looking after the younger children, resentment can develop as a result of these enforced responsibilities. The parents usually have money on payday and are able to provide

a financial initiative for children to take on these tasks. Kids willingly take on these responsibilities because it allows them to demand money for payment, bribery as it were. As they develop a steady financial base, they are able to build a power base over younger kids. They can then manipulate their parents or care-givers into providing more and more money for their perceived responsibilities. When mum's supply runs out, and it will in a day or two, they will look elsewhere – Grandma, uncles, and others. The older children gain in this power structure, which leads inevitably to their manipulation of the younger children. As a result of having access to money it becomes easy for the older kids to get involved in the alcohol and drug market as well as more dangerous activities.

This enables them to develop a regular flow or income and they gradually build a power base over younger kids. A sense of self-worth thus comes from developing a sense of power over others. Parents pay kids to do chores, and willingly the kids take on this responsibility, demanding bribery or money for payment

13.9. Feelings of Failure - Intimacy versus Isolation

During the mid-school age stage (8-11 years), Erickson and Erickson (1997) describes children who learn about success and failure through their achievements primarily in the schools. Those children who are rewarded for hard work with success at school become industrious and learn how to succeed. In comparison the Cherbourg child's success at this age is measured in how strong a power base they have built over younger children and who have control with financial rewards of lollies, drinks and take away food. Their control over adults whom they continue to manipulate in order to gain even more money for performing the day to day tasks of caring for the home and younger children. The children come to realise that they are in a very powerful position within the household and can dominate both groups, adults and children. By developing a strong sense of identity they believe that they have earned their right to dominate the children in their care and it therefore becomes an accepted right to mimic the behaviour of the adults in the community.

The unsuccessful child who does not have a successful power base will begin to see themselves as a failure instead of seeing the activity as not legitimate. Children of this age group are entering a stage I their lives where they develop and display feeling for

themselves, lack of positive feelings can cause them to become emotionally isolated. Change in attitude takes place at around seven or eight years of age and the nine and ten year old are experimenting with alcohol and drugs.

STORY 5:

It is early morning on payday and everyone is up and busying themselves eager in anticipation.

Joey is eight, and Missy is nine, they don't have to go to school today as they have been assigned duties at home, their responsibilities today will be to look after their younger brothers and sisters, and maybe their little friend from down the street and perhaps others because their mum has to go to town.

They know they have to clean up too, or else they won't get any more money.

Joey and Missy pack up the younger kids and head down to the shop with the money that their mum and auntie have given them for being good kids. With this money they can buy chips, coke, and lollies or whatever else takes their fancy and is within their financial capacity.

All of their purchases are shared with the kids in their care. Mind you, if the kids don't do as Joey and Missy ask they will not get any sweets.

13.10. I'm Clearing Out - Generativity versus Absorption

For Erickson the stage of puberty is a time when individuals are finding their identity. It is a time when they decide who they want to become, what their goals are and how they might achieve them. Individuals who fail to find an identity to which they can aspire at this stage are said to suffer from role confusion (McConnell, 1986). In Cherbourg when the individual reaches the youth stage (11-13 years), they are well accomplished at mimicking the behaviour of adults around them. The children in this age group are searching for affection which leads to sexual liaisons, however, their own identity has not yet developed.

People felt that satisfying the need for affection under any circumstances was more important than wearing a condom even though they acknowledge that the community has a high level of sexually transmitted infections. This acceptance of their prevailing circumstances should not be mistaken for apathy or lack of caring about self. Sexual abuse and violence left victims with feelings of shame, low self-esteem, lack of confidence and trust. It deprived them both emotionally and spiritually while, at the same time, cause them to feel they had lost peer respect and identity. Nonetheless

the need to belong somewhere, and with someone is stronger than even these intensely negative emotions.

Sexual behaviour was seen to have little to do with concepts such as health and responsibility, characteristics commonly associated with discussing sexual activity in the Western cultural context. For example, the majority of people agreed that condoms and the practice of safe sex was not seen as an issue in Cherbourg. People said: “young people are craving for love and affection, and if the girls say no to the male they get bashed anyway. And the man will go and find someone else and they will be left alone, meaning they would not have a source of affection.” A concerned respondent felt that: “the girls don’t care if they get bashed, it’s like they need to be with someone only if it’s for a short time.” One distressed informant stressed that: “there are children placing themselves at risk and being sexually active.” When asked how old the children are, the response was: “they would be ten and eleven.”

This statement is supported by the concerns of another respondent who states: “yes that’s right like even younger than the ten year olds you’ve got a lot of the eight and nine year olds following the older siblings and they are getting into the same practice.” Another person emphasised: “here are nine and ten year olds around here, who drink and smoke yarndi. Some are sexually active, they walk around at night looking for a man.”

People talked in general terms about the precipitating factors which lead to family breakdown in terms of what they believed were the cause and effects of sexual abuse in the community. An older informant reflected that: “children are being molested at a very young age and by the time they develop maturity it is just an everyday thing for them.”

13.11. Let’s Play

From the ages of thirteen to forty plus years in Cherbourg, this category of Adult is not one based on responsibility as is most commonly the case of Western social structures. The Parent/Adult role is one of power, in Cherbourg, if only as a head of a household but not necessarily one of responsibility for others. Responsibility and maturity do not always carry the same expectations while children are forced into responsibility at a very early age as it would be the broader population. The drinking

adult tends to be allowed to gain maturity and responsibility more slowly usually after quitting drinking, for example, other adults forgive drunken behaviour and excuse even violent acts committed whilst under the influence of alcohol. Elders often claim that the irresponsible behaviour of a thirty to forty year old person is because they have not yet grown up.

The term adult in Cherbourg carries with it the sense of social inclusion. The adults gather together socially, drink together, gamble together and are sexually active in a more public sense than was earlier the case. Young adolescents are usually eager to be accepted into this social world of belonging with adults. A study respondent pointed out, all she does is get on the grog, that poor little baby might have to have an operation and all she does is party up.

Being a drinker is not equivalent with being Aboriginal in any sense, traditional or contemporary, however when Aboriginal people are haplessly initiated into a drinking cycle of behaviour, there is a sense in which the groups identity and placement in mainstream society is judged as behaviour of the dis-empowered. For people in Cherbourg this has considerable repercussions for them living as they do in very racist and insensitive region.

Participants were not specific in their responses when they were asked how much people in the community drank. One person said: “young girls don’t drink that much, just about the same as the fellas do.” Similar patterns were described: “they drink lots, some drink a carton, flagon, spirits, they drink lots.” However, respondents felt there were gender differences in alcohol consumption: “young girls drink spirits, more spirits than beers, one person added that women drink, spirits and cola.” When respondents were asked if they had ever seen a person pass out from too much grog, one person replied: “yeah lots of the time.” Another woman reflected: “I used to black out a lot and now I have to go and have checks on my brain all the time, cause I take fits now.”

Respondents accounts of grog-related stories are tinged with immense sadness and sometimes it is the drinkers themselves reflecting on their own behaviours whilst under the effects of alcohol. They spoke of violence being associated with alcohol and they saw it as part of the landscape of family violence which then envelopes all the tragic issues including child sexual abuse.

It's Pension Day

Counting the economic costs of the 'grog'
They sit under the gum trees
Waiting for the post Office to open
Looking cleaner than any other day
Some yarn and laugh while others sit silently
They don't say what they are gonna do with their money
They all end up at the club
Laughing, drinking, and fighting
It's Pension Day
(Pension Day, Charmine Papertalk-Green, cited in (Saggers and Gray, 1998))

13.12. Going Back - Integrity versus Despair

It is felt by Erickson and Erickson (1997) that when one is placed in a position where they may begin to reflect back on their lives and are possibly facing the prospects of death they then come to terms with the meaningfulness of life, through overcoming their potential despair.

It was agreed by the majority of study informants that people enter a new stage in their life-cycle, as they get older. They begin to think clearer and begin to recognise their own physical and emotional health needs, as they realise that life experiences have taught them, their kind of life-style is not sustainable. Hence, they become tired and cannot carry the burden of violence, and abuse, which they have endured for so long throughout their lives. Grandmothers don't involve themselves in a materialistic world they measure their success and strength by being connected to the spiritual world, returning back to culture. Through this process they see the importance of grandchildren, who in turn trigger an awareness of responsibility and nurturing. They realise the children are the lens to the future.

An elder explained that: "young women act out in relation to their behaviour and alcohol and how they wanted to be perceived by their peers (as party goers) as they entered the community after being away for the weekend to attend a party."

Then as young teenagers they perceive themselves to be, and may be perceived by the community as true adults. Belonging in the social sense becomes the marker of adulthood. Young women seek the emotional connectedness with men that they miss from their families and young men seek acceptance from peers and older men. This social category of Adult is also characterised by violence. The strategies described are about dependence and independence, young women feel isolated and in need of someone, a man and a baby can provide adult status, along with money through either the relationship or through welfare.

13.13. This is how it is here

In Cherbourg the traditional culture has been virtually destroyed and replaced by a new culture of powerlessness – a perception of an inability to take control over their lives. They continue as victims of their traumatic historical experience, the very reasons for their decline into a lifestyle patterned by self-destructive behaviour.

When discussing why people drink, study respondents vehemently stated that inter-personal violence, family violence, socially disruptive behaviour, disintegration of families, boredom.

Respondents felt grandmothers achieve feelings of self-worth, personal growth and development through the need to care for and to be responsible for their grandies and others. In essence they return to the characteristics of caring that were part of their early childhood. During the early years of life they learned that self-worth was measured in terms of doing for others and even when the responsibility of caring for small children is too much for their health, they continue to feel the need to do for others.

The children see this caring in grandmothers and in older siblings. Although children are in the same vicinity as the adults they appear to place themselves at some distance from the same adults. Survival strategies are observable almost from birth. The grandmothers are the educators caring for the whole mob, teaching them to look after one another and to share their life skills with each other. Younger children develop caring and responsible behaviours like their grandmothers. The young children are left to care for one another under the guidance of the grandmothers. Grandparents are, from the most part drug and alcohol free, and provide a safe and secure

environment. It is at the point when grandchildren are born that many Aboriginal people take stock of their drinking life-style and decide that they have had enough.

13.14. Conclusion

In conclusion, I have shown that the holistic life-cycle model developed as result of work in Hope Vale, a remote Aboriginal community, in 1997, has proven a valuable framework for identifying the issues of alcohol use that lead to understanding the relationship between maternal alcohol consumption and FAS in Cherbourg, a rural Aboriginal community.

This model, based on the stages identified by Erickson (1959) requires moving fifteen degrees anti-clockwise in the Cherbourg context as children as young as four are taking on responsibilities and carer roles for other children. Children as young as nine and ten are frequently and regularly experimenting with alcohol and drugs and other promiscuous active; children aged eleven to thirteen years enter into the social adult world.

The Erickson model is least adequate during the adult phase as Adults are not culturally expected to show signs of 'maturity' in the Western sense before they reach their late forties, or until grandchildren are born. This final phase, then is not primarily a reflective one, as in Erickson's model, it is an extremely active phase in which grand-parents, particularly grandmothers take on the primary responsibility for children.

In this community, people perceive that self and body are not separable entities. It was not possible to isolate a set of clinical disorders, such as FAS, and have people discuss these in isolation from the impact of drinking generally, nor was it possible to have them discuss the physical impact of drinking, without allowing them room to contextualise this within stories about their whole of life experiences.

Most young women and young men talked openly about the perceived relationship of alcohol and pregnancy in the same way as they talked about alcohol and drugs, alcohol and crime, violence, sexual abuse and responsibility, all of which they associate with their families, relationships, friends and with the environment that surrounds them on a daily basis. The words they used were to describe an environment that evoked a sense of hardship and disadvantage. They described

family breakdown, lack of control within the family, and the community, stresses of unemployment, shame, pain and anger within, no trust and respect bestowed upon them from within their family, friends and their peers, rape, sexual abuse, poor opportunities to gain equality to access in the education arena and training.

Various writers have argued that high levels of alcohol consumption among Indigenous peoples are a means of dealing with the frustrations of not being able to reach the goals that they share with mainstream Australians. I would argue that there is much more to the issue than this. Australians have never suffered the trauma of dislocation from their land, culture and family that Aboriginal people have endured.

In Cherbourg the traditional culture has been virtually destroyed and replaced by a new phenomenon of dependency, this phenomena has placed the people in a position where they perceive they have lost their ability to control their fete and destiny. Not all community members of Cherbourg are victims of cultural invasion and dislocation but those that do fall into this category fall into a lifestyle pattern of self-destructive behaviour.

Young people themselves identified the redundancy of an education in a place like Cherbourg, where no jobs exist anyway. Adolescence's eventually become parents at an early age, and end up being welfare recipients.

People do not become angry when they drink. During the interviews it became evident that people are already angry, when they drink their anger is sometimes manifested in violence. Violence becomes a large part of the drinking lifecycle which often results in issues of jealousy. People fight about who owns the grog, women fight over men, and men fight over women. Men also become violent as a way of reasserting their power that they see as having been undermined through historical circumstance. The traditional role for men in Aboriginal society has deteriorated dramatically. In many instances, the men are using violence on their partners and children to re-assert their authority.

It is a common occurrence to see women or young girls with black eyes and puffed up faces following the brawls on the weekends. There are victims who are hospitalised, some even raped or sexually abused, it's like everything revolves around a lifecycle of using alcohol and drugs.

There is a vast majority of young people and children who have or still are being cared for by their grandmothers or aunties. There are situations where parents live in the community and yet the young children would rather stay with their grandmothers. The grandmothers try to provide a safe, secure and nurturing environment for the youngsters. In some instances the grandmothers are seeking employment to provide a secure financial base. Children come from single parent families, their home environment being insecure due to the pressures of poverty, overcrowding, alcohol and drug within the home.

In analysing the responses, it became evident that people were describing a set of interconnecting factors that might somehow be described back to the life-cycle model. A whole range of factors feeding into the lifecycle described previously creating a drinking cycle that leads to alcohol being an accepted way of life and death.

The central tenet of this thesis is that alcohol use within Aboriginal communities can best be understood in terms of a life-cycle model of drinking behaviours. This life-cycle model draws on the work of psychosocial theorists, particularly Erickson (1959) and to a lesser extent the cognitive psychology theorists such as Inhelder and Piaget (1958). However, these models have been developed in a Western psychological tradition. I argue that they are inappropriate in many ways to the life pathways of Aboriginal people living in community settings.

The life stages experienced by people living in both rural and remote Aboriginal communities were investigated in light of these Western psychological models. The models were subsequently adapted to establish an appropriate life-cycle framework to assist in understanding drinking patterns and behaviours in Aboriginal communities. The life-cycle framework is useful as it draws in all the various interconnecting factors and interacting complexities that feed into this cycle throughout one's life and over time, which both feeds into the environment, and feeds from the environment. This cycle is reproduced over successive generations, resulting in adults who systematically care for others, but take little care of themselves.

I maintain that, one of the key points in relation to the use of this life-cycle model is that the Western approach, which focuses on individual developmental stages, must be broadened and integrated with cultural constructionist theories. From the cultural

constructionist perspective, it is unrealistic to expect that individuals can take responsibility for their own actions outside the context of their cultural environment. From this position, programs aimed at changing individual risky behaviours fail to acknowledge the way in which the individual is inextricably tied to the culture in which he or she exist. I argue therefore, that a more useful approach to the problem of alcohol use in Aboriginal communities would be to explore the process by which individuals move within cultures, from one social category to another, such as from the category of non-drinker to drinker and to non-drinker, to explore at what stage in their lives these transitions occur, and to examine the cultural mechanisms influencing the transitions.

The lifecycle of drinking behaviours cannot be understood in the isolated context of a single individual within a single fragmented point of time. Drinking patterns wax and wane over an individual's lifetime and also across generations. Historical influences cannot be overestimated in their impact on contemporary Aboriginal drinking patterns, or indeed on an aspect of Aboriginal Health.

I also claim that the model shows children who are continually exposed to examples of negative adult behaviour develop patterns of behaviour for their later life, i.e. children learn to be irresponsible for their own actions as a result of witnessing negative adult behaviour. Paradoxically children also develop early caring responsibilities for other children, which may eventually lead to the damage of the family's abilities and strengths to guide sensible adult behaviours.

The need to survive on a day to day basis is also intensely stronger than concerns about health on a long-term basis; again not apathy but rather pragmatics. The community itself is an artificial environment without a real economic base, judged on either traditional or mainstream standards. People did not move to the study community Cherbourg to take advantage of industry, or because of the lands capacity to sustain them, rather they were forced together in a situation of mission and later government dependency which continues almost one hundred years later and on to the present.

Being impoverished is a major contributor to ill health within the community and problems such as metabolic disorders, chronic alcoholism, mental health disorders,

cardiovascular and respiratory diseases, genitor-urinary tract infections, infectious and parasitic diseases as well as the aforementioned sexually transmitted infections, are accompanied by the many social and economic disadvantages experienced by Aboriginal people living in a rural area.

Social issues are compounded with younger people who drop out of school early for various reasons including racism, inappropriate curriculum, self-shame, learning difficulties and behavioural problems, and then become bored with their lives without goals or opportunities. It is an easy next step to using alcohol and drugs.

It is acknowledged that mental health issues for indigenous people must be understood beyond those conditions which are dealt with in a clinical context, in keeping with the culturally defined concept of health put forward in the Aboriginal Health Policy. This means acknowledging the negative impact on mental health from a social and economic disadvantage which affect many Aboriginal people, such as alcohol abuse, depression, family instability and unemployment. People in Cherbourg experience many other inter-personal tragedies throughout their lifespan. Some have experienced being taken away, or have family taken away, as children, having family members in detention centres or jails, losing loved ones early to lifestyle diseases. Grief and loss occur frequently in a community where everybody knows everyone or is related by blood or marriage. When there is a death in the community it is not only one's immediate family or kin that has been devastated, the grief touches a much wider circle of extended family members and relations. Deaths which occur suddenly, such as those due to violence, suicide or accident, it is not uncommon for family members to repress their grief, guilt, and anger until something triggers an emotional state. This can result from the abuse of alcohol and drugs which when mixed can bring on despairing emotions which might end in a suicide or other self-harm.

Shkilnyk (1985) who studied alcohol abuse in Indigenous Canadian groups, found that,

> The feelings of aggression and rage normally suppressed in face-to-face encounters find expression during drinking parties which are the context for beatings, rape, or other acts of violence that may lead to death. The drinking parties become part of a vicious circle I which the mourners often become those who are the mourned.

Children in Cherbourg are not only witnesses to this despair but are inevitably caught up in what is going on in their environment, for example, they are often the first ones on the scene after a tragedy in the community. The despair that afflicts the older children soon captures them. They see youth out of work, aimlessly wandering the community, committing acts of vandalism and they too start mimicking these behaviours. This witnessed behaviour acts as a pathway for them to become involved in criminal activities thereby entering into a world of the juvenile system, detention centres, and when they reach eighteen years of age, the prison system. This appears to be their rite of passage, the beginnings of life's journey through the penal system creating a vicious cycle, one in which York (1990) explains,

> *They are suffused by a free-floating hostility, the outcome perhaps of the combined effects of territorial disruption, overcrowding, socio-cultural change, the condition of powerlessness in the fact of incomprehensible forces. This diffuse hostility has no specific object and appears to be turned inwards in the form of self-destructiveness.*

14. Concluding Chapter

"Culture is respecting our elders (Grandmothers, aunties, and uncles). They are our first teachers, they guide our way and are the backbone of our family."

In conclusion, this thesis has shown that the holistic lifecycle model, developed as result of work in Hope Vale during 1997, has provided a valuable framework for understanding the issues of alcohol use within the two Indigenous communities that lead to understanding and identifying alcohol consumption by pregnant women. The model is based on the stages identified by Erickson (1959), however requires moving fifteen degrees anti-clockwise in the Cherbourg context, as children as young as four are taking on responsibilities and carer roles for other. Children as young as nine and ten become experimental with their yearnings when moving from one stage to the next, especially when they leave the safe environment that they have created. Older children of the age of eleven to thirteen years enter into the social adult world longing for the parental care and closeness which they so desire, not realising that they are entering into a dangerous unsafe environment.

The Erickson model is least adequate during the adult phase as Adults are not culturally expected to show signs of 'maturity' in the Western sense before they reach their late forties, or until grandchildren are born. This final phase, is not primarily a reflective one, as in Erickson's model, it is an extremely active phase in which grandparents, particularly grandmothers take on the primarily responsibility for children.

Understanding issues such as FAS in Aboriginal communities can only result from listening to the Aboriginal perception of health and illness and beginning from the beginning as identified by Aboriginal people themselves. Aboriginal people insist that the problem of alcohol in the communities must be viewed from the perspective of a range of social, cultural and historical factors that bridge generations and shape whole lives.

One of the significant findings of this study was, community members even those working in the health profession had very little specific knowledge of FAS and FAE. They did, however, display knowledge of how alcohol can affect the development of a foetus.

In analysing the responses, it became evident that people were describing a set of interconnecting factors that might somehow be described back to the life-cycle model. A whole range of factors feeding into the lifecycle described previously creating a drinking cycle that leads to alcohol being an accepted way of life and death.

In this community, people perceive that self and body are not separable entities. It was not possible to isolate a set of clinical disorders, such as FAS, and have people discuss these in isolation from the impact of drinking generally, nor was it possible to have them discuss the physical impact of drinking, without allowing them room to contextualise this within stories about their whole of life experiences.

It became obvious from listening to the people, the pregnant women were drinking far too much alcohol. Among community members there is minimal knowledge about FAS and FAE, however, there is general understanding that alcohol consumption can impact on the health of the unborn child. Women described a picture where their babies were being born smaller and smaller, often after they had drank right up until they were born. Community members were aware of children who they felt had FAS, although they had no specific knowledge of the clinical signs of the disease. There were also women who believed that a large proportion of children and youth in the community were victims of FAE. As defined by Morse et al. (1989), when one is diagnosed with FAE, one may show signs of behavioural problems, learning difficulties, enuresis (bed wetting), anxiety disorders, and of being withdrawn.

The women felt that this syndrome or its effects are inter-generational (passed down from one generation to another), as community members had siblings, or children who they believe have this condition and the women remember drinking beer, wine and spirits all through their pregnancies.

Peoples also spoke of children drinking, at a very young age. All the people in the community who were interviewed claimed they were aware of children under twelve who drank alcohol. As York (1990) points out, children growing up with drinkers all around them often start drinking themselves in their pre-adolescent years.

Individuals were deeply aware of the affects their drinking had on themselves and on those around them. They did not however, isolate physical effects, and they saw causes of drinking in broad socio-historical terms.

Most young women and young men talked openly about the perceived relationship of alcohol and pregnancy in the same way as they talked about alcohol and drugs, alcohol and crime, violence, sexual abuse and responsibility, all of which they associate with their families, relationships, friends and with the environment that surrounds them on a daily basis. The young people that I talked to are linked to their environment. The words they use to describe that environment evoke a sense of hardship and disadvantage. They describe family breakdown, lack of control within the family, and the community, alcohol and drugs, teenage pregnancy, peer pressure, violence within the home and community, stresses of unemployment, shame, pain and anger within, no trust and respect bestowed upon them from within their family, friends and their peers, rape, sexual abuse, poor opportunities to gain equality to access in the education arena and training.

When discussing why one drinks participants agreed that inter-personal violence, family violence, behaviour which is socially disruptive towards other community members, disintegration of families, boredom, grief and loss, child abuse, molestation, poverty, unemployment, helplessness and despair all stem from the effects of alcohol. But at the same time all these factors contribute to the continued patterns of drinking which result in injury, social disruption, personal property being lost or destroyed, children being taken away into child protection, and ill health. This pattern is cyclical, it does not proceed in a straight line from cause to effect.

Various writers have argued that high levels of alcohol consumption among Indigenous peoples are a means of dealing with the frustrations of not being able to reach the goals that they share with mainstream Australians. I would argue that there is much more to the issue than this, as Australians have never suffered the trauma of dislocation from their land, culture and family that Aboriginal people have endured. In Cherbourg the traditional culture has been virtually destroyed and replaced by a different form of dependency and a different way of life. This dependency has placed the people in a position where they perceive they have lost their ability to control their fate and destiny. The community members of Cherbourg are victims of cultural invasion and dislocation which has steered them into a lifestyle pattern of self-destructive behaviour.

People spoke in general terms about the precipitating factors which lead to family breakdown in terms of what they believed were the cause and effects of sexual abuse in the community. The people reflected that they are being molested at a very young age and by the time they develop maturity it is just an everyday thing for them. Community workers and community members felt that kids don't care if they get taken away, they get molested here and when they are away at homes they get molested too, the only difference is they get a feed every day and a clean bed to sleep in. Sexual behaviour was seen to have little to do with concepts such as health and responsibility, characteristics commonly associated with discussing sexual activity in the Western cultural context.

The need to survive on a day to day basis is also intensely stronger than concerns about health on a long-term basis. This again, is not apathy, but rather pragmatics. The community itself is an artificial environment which is not linked to any successful economic base (either traditional or Western). People did not move to Cherbourg to take advantage of industry, or because of the land's capacity to sustain them. People were forced together in a situation of mission and later government dependency which continues until this day. Poverty is one of the major contributors to ill health within the community leading to influences of metabolic disorders, chronic alcoholism, violence, diseases in which immunological responses are disrupted such as HIV AIDS, and the dominant systemic diseases such as cardiovascular disease, diseases of the respiratory system, genito-urinary infections, infectious and parasitic diseases.

The social and economic disadvantages experienced by Aboriginal people, due to poverty, throughout their lives contribute to mental distress and mental health problems. Many Aboriginal families and individuals are forced to subsist in deplorable conditions which characterise the deeply entrenched health problems experienced by Aboriginal people today. In Cherbourg there are social issues affecting the mental and emotional health of community members. There are young people who tend to not go to school, becoming bored with their lives which then also leads to them becoming involved with alcohol and drugs.

People in Cherbourg experience many inter-personal tragedies throughout their lifespans, such as family breakdown, removal of children into protective custody, violence, alcohol and drug abuse. Cherbourg is a place where everybody is related

by blood or marriage with the exception of the few that have come from outside of the community. When there is a death in the community it's not only one's immediate family/kin that has been devastated, the grief touches a much wider circle of extended family members/relations. When the death is a result of violence or accident it is not uncommon for family members to repress their grief, guilt, and anger only allowing the release of such emotions when they are in an altered state of consciousness being the outcome of alcohol and drug abuse.

Furthermore, children are often caught in a vast vacuum between two cultures. The children in Cherbourg are not going to school, therefore, they are not learning the basic skills for survival in mainstream society nor are they learning the skills from the traditional Aboriginal culture.

Young people themselves identified the redundancy of an education in a place like Cherbourg, where no jobs exist anyway. Young people eventually become parents at an early age and end up being welfare recipients.

People do not become angry when they drink. During the interviews it became evident that people are already angry, when they drink their anger is sometimes manifested in violence. Violence becomes a larger part of the drinking lifecycle which often results in issues of jealously. People fight about who owns the grog women fight over men, and men fight over women. Men also become violent as a way of reasserting their power that they see as having been undermined through historical circumstances. The traditional role for men in Aboriginal society has deteriorated dramatically. In many instances, the men are using violence on their partners and children to re-assert their authority.

It is a common occurrence to see women or young girls with black eyes and puffed up faces following the brawls on the weekends. There are victims who are hospitalised, some even raped or sexually abused, it's like everything revolves around a lifecycle of using alcohol and drugs.

There is a vast majority of young people and children who have or still are being cared for by their grandmothers or aunties. There are situations where parents live in the community and yet the young children would rather stay with their grandmothers. The grandmothers try to provide a safe, secure and nurturing environment for the

youngsters. In some cases the grandmothers are seeking employment to provide a secure financial base.

Children come from single parent families, their home environment being insecure due to the pressures of poverty, overcrowding, alcohol and drugs within the home. It was agreed on by the community members who took part in the study that this practice made the home life especially difficult for a child especially when there is a larger number of kin charging up, they cause too many problems.

Once they reach a certain age and think they are grown up, all the positive caring behaviours fall by the wayside. At this point they lose responsibility and caring characteristics that have been previously evident in their behavioural role, they suddenly appear to become focused on the self.

They are caught between what they know how to do and the condition of life on the community (Shkilnyk, 1985)

15. Concluding Statement

I recall a reference made to an audience by Paulo Freire. Friere states*: "It is a joy to work with people whose only illiteracy is with language."* This is not a sarcastic reply on the part of Friere. I believe that it is a statement that alludes to the power of language and how it becomes (for us all) an essential challenge and responsibility to be able to hear each other's embodied cultural knowledge as part of promoting social and educational transformations relating to FASD.

I ask three questions from a poem by T.S. Eliot, "Choruses from 'The Rock"

Where is the life we have lost in living?

Where is the wisdom we have lost in knowledge?

Where is the knowledge we have lost in information?

I ask you the reader, how can we as individuals or as a collective make a point regarding the necessity to re-think how we teach each other, do we make instructional and cultural practices, in order to make our work in the FASD field more effective?

We all devote a large portion of our discussion specifically in addressing issues of difference, pedagogy, and curriculum as a learning and cultural practice, we must then consider the roles of educators in bringing about cultural and educational change.

The success of this change calls for sacrifices, honesty, and a collective desire to do the right thing for all. Communities, parents and families, educators, clinicians all have a role to play. Quite often we expect parents to make the first move to be involved - perhaps this is rightly so, but then educators and clinicians must play their part to support communities.

I was told many years ago, as an excited and eager undergraduate student who wanted to research on the specific area of FAS, that I would not be supported if I went ahead with my research topic, this was backed up with a statement:

"It is ethically and immorally wrong to do such research that will stigmatize the mother and child".

I eventually went ahead and did my research and during the next twenty-one years I continually had great and interesting public debates with paediatricians, general practitioners and other health professionals about such stigmatization.

16. Summary

This research is unique in its entirety; from 1992 through to 2011 its development was motivated by my experiences as an Aboriginal woman listening to the voices of other Aboriginal women in Hope Vale and Cherbourg listening to the stories, the encounters, the debates, and the myths about Aboriginal peoples' drinking histories, their culture and their identity. I wanted to explore and expose what they see as the important health issues that are related to alcohol use and how it relates to them, their families and their communities especially in relation to Aboriginal women. Research on FASD is still being explored today (2019).

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18. Appendix 1

18.1. ATODS Record Chart

ALCOHOL TOBACCO AND OTHER DRUGS

TOBACCO
Before you were pregnant

1. Did you ever smoke cigarettes regularly?	Yes		No		Don't know

Now that you are pregnant

2. Do you smoke everyday	Yes		No		Don't know
Every few days	Yes		No		Don't know
Don't Smoke at all	Yes		No		Don't know
3. How many smokes do you usually smoke each day?	Yes		No		Don't know
50 or more per day	Yes		No		Don't know
30 or more per day	Yes		No		Don't know
20 or more per day	Yes		No		Don't know
1-10 or more per day	Yes		No		Don't know
Never smoked	Yes		No		Don't know
4. Do you consider yourself	Yes		No		Don't know
An occasional smoker	Yes		No		Don't know
Light smoker	Yes		No		Don't know
Heavy smoker	Yes		No		Don't know
A chain smoker	Yes		No		Don't know
No answer or comment	Yes		No		Don't know
5. At home do you smoke inside or do you go outside to smoke?	Yes		No		Don't know
Smoke anywhere	Yes		No		Don't know
Usually smoke inside	Yes		No		Don't know
Smoke outside	Yes		No		Don't know
Depends	Yes		No		Don't know
Don't smoke at home	Yes		No		Don't know
No comment	Yes				
6. Do you want to learn about ways to quit smoking?	Yes		No		Don't know
7. Does anyone else who lives in your home smoke inside your home?	Yes		No		Don't know
8. Did you used to smoke but have now given up?	Yes		No		Don't know

ALCOHOL
Before you were pregnant

1. Did you ever drink alcohol? If no got to Q5.	Yes		No		Don't know
2. Did you drink:	Yes		No		Don't know
Beer	Yes		No		Don't know
Wine	Yes		No		Don't know
Spirits	Yes		No		Don't know
Or any other alcoholic drink	Yes		No		Don't know
3. How did you drink your alcohol?	Yes		No		Don't know
Stubbie bottle	Yes		No		Don't know
Tal bottle	Yes		No		Don't know
Can	Yes		No		Don't know
Glass	Yes		No		Don't know
5 oz	Yes		No		Don't know
7 oz	Yes		No		Don't know
10 oz (pot)	Yes		No		Don't know
Other ……..	Yes		No		Don't know
4. How often did you drink alcohol?	Yes		No		Don't know
Daily	Yes		No		Don't know
A few times a week	Yes		No		Don't know
A few times a month	Yes		No		Don't know
Never	Yes		No		Don't know

Now that you are pregnant

5. Do you drink alcohol?	Yes		No		Don't know
6. How often do you drink alcohol?					
Daily	Yes		No		Don't know
A few times a week	Yes		No		Don't know
A few times a fortnight	Yes		No		Don't know
A few times a month	Yes		No		Don't know
Never	Yes		No		Don't know
7. When you drink how much do you drink?					
Seven or more glasses or cans	Yes		No		Don't know
Five or six glasses or cans	Yes		No		Don't know
Three of four glasses or cans	Yes		No		Don't know
One or two glasses or cans	Yes		No		Don't know
Less than one glass or can	Yes		No		Don't know
Don't drink	Yes		No		Don't know
8. What type of alcohol do you drink?					
Beer	Yes		No		Don't know
Spirits	Yes		No		Don't know
Wine	Yes		No		Don't know
Other…….	Yes		No		Don't know
9. At present time do you consider yourself to be one of the following:					
An occasional drinker	Yes		No		Don't know
A light drinker	Yes		No		Don't know
A heavy drinker	Yes		No		Don't know
Don't know/no comment	Yes		No		Don't know

10. Did you drink alcohol but have now given up?	Yes		No		Don't know
11. Do you want to learn about ways to quit drinking?	Yes		No		Don't know

DRUGS

Before you were pregnant

1. Did you ever use marijuana? Or any other drug such as:	Yes		No		Don't know
Speed	Yes		No		Don't know
Cocaine	Yes		No		Don't know
Heroin	Yes		No		Don't know
Other……..	Yes		No		Don't know
2. Do you use marijuana or any other drug such as:	Yes		No		Don't know
Speed	Yes		No		Don't know
Cocaine	Yes		No		Don't know
Heroin	Yes		No		Don't know
Other……..	Yes		No		Don't know
3. If yes to any of the above, how do you use the drug of your choice?					
Joint	Yes		No		Don't know
Bong	Yes		No		Don't know
Cone	Yes		No		Don't know
Bucket	Yes		No		Don't know
Other……	Yes		No		Don't know
4. How often do you use drugs?					
A few times a day	Yes		No		Don't know
A few times a week	Yes		No		Don't know
A few times a fortnight	Yes		No		Don't know
A few times a month	Yes		No		Don't know
Other……	Yes		No		Don't know
5. Do you consider yourself:					
An occasional drug user	Yes		No		Don't know
A light drug user	Yes		No		Don't know
A heavy drug user	Yes		No		Don't know
No answer or no comment	Yes		No		Don't know
6. Have you ever tried sniffing, if yes	Yes		No		Don't know
What have you tried?					
Glue	Yes		No		Don't know
Petrol	Yes		No		Don't know
Pain	Yes		No		Don't know
Other……	Yes		No		Don't know
7. Does anyone else who lives in your home use drugs inside you home?	Yes		No		Don't know
8. Do you want to learn about how to quit using drugs?	Yes		No		Don't know
9. Did you use drugs but have now given up?	Yes		No		Don't know

19. Appendix 2

19.1. Cherbourg Community Research Protocol

Research has been carried out in Australian Aboriginal communities for over two centuries, and during this time the rights of researchers to enter communities and take information away for the purpose of academic advancement have been taken for granted by Universities and Government institutions. This document concerns the rights of the community within this process.

The Cherbourg Community Health Action Group has formulated the following research protocols for all people interested in carrying out health research in this community. The Cherbourg Council supports the Health Action Group in their right to grant or deny permission for research projects to be carried out in Cherbourg on the basis of their evaluation against this set of protocols.

The western academic tradition of collecting data that is considered separate and unconnected to the people it represents is in direct conflict with the Aboriginal view that people's stories are part of themselves. When researchers take away stories, they take away part of those people telling stories. This remains true whether the information is taken in the form of numbers and figures, people's words, photographs, or in any other form. The Cherbourg community owns this information, collected within the Cherbourg community from community members. In this context ownership coves the entire process of research project as well as the use of resulting data and documents.

Researchers wanting to conduct research in Cherboug must first meet with the Cherboug Health Action Group. The Cherbourg Communtiy has develped an Action Plan and potential research needs to fit within the goals set down in the plan. Researchers should discuss their research interests with the Health Action Group before they develop a written research proposal. Once the researcher had discussed the potential for their project with the Health Action Group they should compile a written proposal and submit this for approval. The Health Action Group meets every six weeks at the Cherbourg Community Health Centre.

The Cherbourg Council supports approval given by the Cherbourg Health Action Group. No research will take place in Cherbourg without formal approval from the Health Action Group. Once initial approval is granted researchers will continue to meet with the Health Action Group on a regular basis to report on the progress of the research. It is the right of the community to stop the Research at any time.

Once data has been collected, it remains the property of the Cherbourg community and will be stored on the community. The community reserves the right to grant or deny access to the data for uses other than those originally agreed upon.

Researchers should note that knowledge from the Indigenous perspective is not freely available for the taking and certain levels of access to data might be granted to community. Researchers should also note, that time frames agreed upon by funding organisations or academic instituttions might not be realistic in the community setting. Community business will always take priority over research.

19.1.1. Guidelines for Research Proposals

- Research topics must comply with the Health Services 10 Point Plan
- Research must lead to action. The researcher is responsible for clearly stating how the community will benefit from the study.
- Research should incorporate an element of training for local community members.
- Research of a sensitive nature must be accompanied by a counselling service at the expense of the researcher.
- Data resulting from the research remains the property of Cherbourg and will be stored on the community.
- Results of the research will be provided to the community in a useable format.
- Dissemination of the information will be discussed with the Health Action Group prior to its release.

The Community of Cherbourg will at all times view the researcher as working for the Community.

19.1.2. Ethical Considerations

The success of research within Aboriginal Communities is dependent upon the use of appropriate processes in relation to the development of the project, the period of data collection and evaluation and dissemination of results. Community consultation has been a key factor of this project from the outset. During my time working in the Cherbourg community, members have identified issues of concern to them. One of these issues has been a consistent concern for the return of birthing to Cherbourg. Discussions with community members, health workers, members of the Health Action Group and the staff of the Cherbourg hospital revealed that Queensland States Health maintain the position that birthing cannot return to Cherbourg because the risk for Cherbourg mother's and babies is too high. This risk categorisation, it was felt, was not based on empirical evidence, but rather on an assumption about risk for all Aboriginal women. It was decided that an empirical study was needed to establish the actual risk of Cherbourg women as recorded in antenatal records, and compare this risk assessment with outcomes of delivery at Kingaroy Hospital.

This approach involving the community from the formation of the idea and through the development of the research design is integral to a sense of ownership of the project within the community. There is also a sense of reciprocity in this approach. Aboriginal people often speak of having been researched too many times, and having gained little or no benefit from this research. Research process in Indigenous communtiies in the future will increasingly need to comply with protocols that call for this level of reciprocity.

Measuring the risk factors of women who have been removed from Cherbourg to Kingaroy over the past five years, as well as the details of delivery and the outcomes for mother and child involves the researcher acessing medical history files that may contain sensitive information. It is essential that community members are fully aware of this and are confident that the likely outcomes of the research are worth this intrusion. It is also essential that community members are satisfied that confidentiality in relation to the information examined will be fully maintained.

In this case confidentiality will be partially ensured by the fact that names of individuals or their specific medical history details are not required. This information will not be recorded in any form as data within this research.

Permission will be obtained from authorities to gain access to institutional records and information will nto be used for any other purpose other than that for which permission was obtained.

19.1.3. Duty of Care

As the researcher will be observing circumstances that may be of a sensitive nature it must be made clear to the people involved that the observations and interviews are for research purposes only. The researcher will not be in a position to pass judgement of any kind or to repeat observations or hearsay to any organization or individual in terms of specific names or incidents.

19.1.4. Purpose of the Research

Since 1987 the women of Cherboug have been removed at 37-38 weeks gestation to Kingaroy Hospital for delivery of their babies. This procedure is followed because these women are automatically assumed to be at high risk for a number of negative obstetric outcomes. Although this risk is assumed, it is unknown what specific risk factors these women actually have or the specific outcomes of their deliveries in Kingaroy.

While it is important that women who are at high risk of obstetric complicatons receive appropriate care at the larger hospital, it is also important that women's risk be measured rather than assumed.

It is expected that this study will result in specific details of what proportion of Cherbourg women show certain levels of risk and what proportion of Cherbourg women have negative obstetric outcomes, or complications during delivery.

The perceptions of Cherbourg women of their delivery experience at Kingaroy will provide a qualitative context to the quantitiative data. The long standing approach of using qualitative research methods is affiliated with various academic fields such as cultural anthropology, sociology, and psychology (Hudelson, 1994). The use of

qualitative research is progressively increasing and it is being integrated in a number of ways with quantitative work to establish a richer data set and more in-depth understandings of the issues of concern. The value of qualitative research methods lies in its ability to identify and examine the culture and behaviour of groups as well as the psychology and behaviour of the individual. In additon a qualitative approach allows for documentation of the issues from the point of view of those being studied.

A valuable indicator in actualising the role of culture, is that all research data must be interpreted in its particular context. This context includes historical, economic, social, political and geographical elements.

If women are dissatisified with being removed to Kingaroy and can perceive of no benefit to themselves or their babies, and if there is no quantative evidence of such benefit, then the argument for returning birthing to the Cherbourg community is significantly strengthened.

20. Appendix 3

20.1. Cherbourg Ten Point Plan

The Ten Point Plan

Cherbourg: September 2017

This document was produced by the Health Action Group for all organisations that provide services in the Cherbourg Aboriginal Community.
The Darling Downs Hospital Health Service – South Burnett – Cherbourg sponsors the publication of this document..

Introduction

The original Ten Point Plan was developed by the **Health Action Group** between December 1995 and March 1996. There have been number of reviews of the Ten Point Plan. This current version results from changes made by the Health Action Group in late 2011, 2012, 2013 & 2014.
The cumulative list of Indigenous participants/contributors over the years and more recently include:

Ada Simpson	**Anita Jacobs**	**Cecil Brown**	**Cindy Button**	**Christine Stewart**	
Colleen Murray	**Collette Brown**	**Eddie Barney**	**Eddie Mi Mi**	**Elaine Berlin**	**Grace Stanley**
Elaine Georgetown	**Elizabeth Jacobs(Snr)**	**Elizabeth Jacobs**	**Genette Simpson**	**Gordon Wragge**	**Grace Bond**
Gwen Fisher	**Harold Fatnowna**	**Ida Bligh**	**Irene Landers**	**Jacqueline Barrett**	**Jenny Thompson**
Jennifer Hart	**Julie Owen**	**Joanne Simpson**	**Laverne Fisher**	**Lillian Gray**	
Linda Georgetown	**Lorian Hayes**	**Lorraine Murray**	**Maylene Saltner**	**Maleeta Richards**	
Melanie Butler	**Michael Bird**	**Muriel Conlon**	**Noela Baigrie**	**Patricia Duncan**	
Patricia Bond	**Rae Long**	**Rachel Saltner**	**Sam Hill**	**Sam Speedy**	
Stephanie Button	**Stephen Fisher**	**Steven Hart**	**Tarita Fisher**	**Tracey Appo**	**Warren Collins**

In Loving Memory of those who have passed (who have also contributed to the Ten Point Plan):

Allan Douglas	**Annie Moffatt**	**Berline Chapman(Snr)**	**Bert Button**	**Beryl Gambrill**
David Gray	**Don Beezley**	**Joseph Button (Snr)**	**Minnie Blackman**	**Alzira Conlon**
Rory Boney	**Lyn Douglas**	**Lillian Hopkin**	**Patrick Alberts**	

The following non-Aboriginal peoples contributed only when their views were sought by Aboriginal people:
Peter Maher, Pauline Murfin, Jane Welsh, Juliette Tessman, Imogen Wotlemaro, Kathleen Kerwin, Debbie Smith, Sharon Collins, Nikki Dowling, Meg Dinte, Joyce Horne, Stuart Pledger, Sharon Sellers, Elaine Mostaert, David Edwards, Dorothy Stewart, Margo Cox, Kathryn Hunt, Anne Gunn, Sharon Lock, Lyn Schuh, Robyn McIntosh, Joyce Thompson, Jenn Wyeth, Vanessa Carson,

Services / Organisations

CRAICCHS	**Health Action Group**	**Cherbourg Hospital & Health Service**	
Cherbourg Justice Group	**Council Welfare Section**	**CTC Youth Services Murgon**	**Critical Incident Group**
Diabetes & Renal Support Group	**Disabilities Qld**	**DOULA women**	**Jumbunna**
Women's Shelter	**Men's Group**	**Ny Ku Byun – Aged Care**	**Women's Group**

The Process of developing this plan included:

1. Facilitation of the original 1995 workshop by Peter Maher and Julie Owen including presentation of overhead slides identifying health problems of Aboriginal and Torres Strait Islander people in the Wide Bay Region, identification and prioritising of the key areas of concern. Small groups then identified the major Problems, Goals, Strategies and Measurements for each topic.
2. The baseline measurements were researched and reviewed by Peter Maher and for the first three years comparative outputs of Community Health and Hospitals were measured. This manual data analysis could not be sustained. Until it ceased it demonstrated that the Primary Health Care approach worked.
3. The Health Action Group further reviewed the plan at meetings in March 1996, August 1997, April 1999, March 2001, June 2003, July 2004, 2008 & June 2013. This seventh version was determined by HAG in July 2012 after consultation with number of groups and individuals (rather than in public meetings as in previous years), which commenced in June 2012 – revised June 2013 – completed in May-June 2014.

The Purpose of this plan is to ensure ownership by Aboriginal people; and for the Cherbourg Aboriginal community to give guidance and advice to the Cherbourg Hospital and Health Services, Barambah Medical Centre, visiting specialist and other service providers across the DDHHS (that deliver services to Cherbourg peoples). The Cherbourg Ten Point Plan (TTP) is the responsibility of all government and non-government services to implement; through establishing strong partnerships and engaging community. The health priorities identified throughout this TPP document are concerns that have been raised by the Cherbourg Community including members from the Health Action Group.

Staff Statement of Common Values

These are values which Health Service staffs need to implement in their work to improve the health status of the community:

Friendly Positive Understanding Professional Honest Safe Efficient Effective Sustainable

Recognising Individuality Recognising Humanity Supporting Self-Help Promoting Self-Determination

Acronyms used in this document:

ADFQ = Alcohol & Drug	**HLO** = Hospital/Community Liaison Officer
AHW = Aboriginal Health Worker	**HP** = Health Promotion
APHC = Aboriginal Primary Health Care Certificate course	**HSM** – Health Service Manager Cherbourg
AODS = Alcohol& Other Drug Services	**IMT** = Integrated Management Team (Hospital, Community Health & BRMS)
BSL = Blood Sugar Level (a measure for diabetes)	
C&S = Cultural & Spiritual (Mental Health & AODS Team)	**PHN =** Primary Health Networks
CCHS = Cherbourg Community Health Service = "Team"	**MHW** = Mental Health Worker
CCHS Manger = Manager of Cherbourg Community Health Service	**MH =** Mental Health
CHHS = Cherbourg Hospital & Health Service	**Nr** = Nurse
CE = Chief Executive	**PCR** = A test for sexually transmitted infections
CIMHA = Mental Health data software	**PIHC** = Principal Indigenous Health Coordinator
CH = Child Health	**QAS =** Queensland Ambulance Service
CRAICCHS – Cherbourg Regional Aboriginal Islander Community Controlled Health Service	**QPS** = Queensland Police Service
DON = Director of Nursing	
DON South Burnett = Director of Nursing South Burnett	**SHW** = Senior Health Worker
DDHHS = Darling Downs Hospital Health Service	**STI** = Sexually Transmitted Infection(s)

Strategies about the Ten Point Plan

Goals	The Problems & Causes	Strategies	By Whom	Measure
To improve participation of, and feedback to community, in development of this plan.	• Fewer people in community knowing of the plan's existence. • Fewer participating in its development. • Fewer getting feedback about results. • Concerns that no action is taken as a result of planning. • Services need to communicate to each other – no one wants to come together.	Provide copy of Ten Point Plan to all Cherbourg Households. Home visit, door drops and post office mail pick ups, plus radio advertisements before each review. Home visits / mail pick up: of progress review along with invites to next planning session. Health Service to support getting HAG members together.	Cherbourg Health Service staff, HAG HAG Chair & CCHS manager	Promote and provide copies of Ten Point Plan to community and staff across the district.
DDHHS CE	• Recognition of Community and Cultural Governance within the Cherbourg Aboriginal Community.	*Endorsement of Cherbourg Ten Point Plan* in partnership & recognition of HAG, Council and other services providers across the multi- Govt. & Non-Govt. Services	*DDHHS CE* Executive Management	DDHHS CE letter of recognition and endorsement of TPP document on behalf of DDHHS / South Burnett & Cherbourg

1. Cultural & Spiritual Health: Mental Health

Goals	The Problems & Causes	Strategies	By Whom	Measurement
To improve mental health services in the Cherbourg Aboriginal community. To provide community education and awareness of mental health, it's management, treatment and care in Cherbourg To establish a community-based mental health advisory group	• All the following are inter-related: **Key Areas:** • **Stress** • **Loss of Culture** • **Dispossession** • **Identity** • **Isolation** • **Family Structures** • **Unemployment/Low Income** • Lack of community awareness about mental health • Schizophrenia, Bipolar, Personality Disorders, • Depression • Anxiety • Suicide • Grief & loss • Sexual Assault • Low self Esteem • No sense of future • Poor coping skills • Less communication • Gossip • Domestic violence • Family break-ups • Child abuse	1.1 Retain ownership of service at local community level 1.2 Provide CYMH worker / clinician to help our children and youth 1.3 Provide a visiting CYMH psychiatrist for our children and youth to access in Cherbourg 1.4 Support and assist local Carers Group Meetings 1.5 Support and assist community-based mental health advisory group 1.6 Develop local educational resources on Mental Health (including: video, pamphlets) 1.7 Increase community awareness about MH and services	DDHHS CE & MH services DDHHS CE & District MH Services AHW, MH clinicians, CCHS AHW - MH, MH clinicians, CCHS DDHHS MH services, CCHS, AHW – MH CCHS – MH team	Local management based with Cherbourg Community Health Position to be funded and created Visiting specialist provide regular visits No. of Child & Youth referrals (identified MH caseload in local Aboriginal community No. community members attending meetings No. of meetings & group members attending Funding allocated to support the development of local educational resources on MH

	• Gambling • Trying to live two cultures • Racism / Discrimination (including within indigenous community) • Lack of self-determination (but don't want to be set-up to fail) • Less responsibility for children • Less discipline in the family - no respect for elders • Parents and Grandparents are Younger - Granny burnout • Overcrowding	1.8 MH staff / team to provide support and education; and work in partnership with other community services / organizations 1.9 Provide MH 1st Aid Training to community members, Carers, services and organisations 1.10 All MH staff to attend local & DDHHS Cultural Awareness / Practice Program (CPP)	MH team, CCHS, Police, Hospital, Aged Care, Shelter, Schools & Youth Services & Youth Justice (Jumbunna) Visiting Specialist, MH clinicians	No. of partnership meetings attended and education sessions provided to external services/ organisations No. of staff attendance to CAP

2. Sexual Assault

Goals	The Problems & Causes	Strategies	By Whom	Measurement
To increase community awareness of sexual assault; and how it impacts on the spiritual, mental, psychological and physical well being of the individual, family and community.	• Male police may at times be a barrier to women reporting rape. • Lack of appropriate support from QPS (i.e. Murgon/Cherbourg) • Aboriginal lore is not imposed. • Past abuse becoming an issue for the middle to older generation. • It's not just the grog & drugs – it's starting to become a way of life. • Sexual assault affects children, youth, women and men – the whole family. • Sexual Assault is still seen as taboo. • Not enough community awareness about sexual assault.	2.1 Implement the QH policy and procedures on sexual assault 2.2 Need more female police officers to conduct initial interview with victim (& families) 2.3 Need a community support person with victim at time of interview	Cherbourg Hospital & Health Service (CHHS),, social workers, MH team, Hospital, BHC, AHW, Police, QPS	Referral pathway implemented without complaints Staff aware of policy / procedures Female police conducting interview with victim Establishment of a sexual assault worker

To improve the health service's and other agencies / service response to sexual assault	• Domestic, family and lateral violence	2.4 Support the establishment of a Sexual Assault Worker position locally. 2.5 Develop local resources and provide education to community members, family and services on sexual assault	All Cherbourg, DDHHS, Cherbourg Hospital & Health Service (CHHS), AHW, Social Workers, QPS, Women's Shelter, Youth Services,	Local resources are implemented and accessible
		2.6 Identify safe houses for victims	All Cherbourg, families, shelters,	Provide a safe haven for victim & family
		2.7 Ensure safe and appropriate pathways are established for reported sexual assault victim and their families - establish an 'on call' support group and counseling service	Hospital, QPS, CHHS, All Cherbourg, AHW, Social Workers, youth services, schools,	Confidentiality and appropriate support services are in place for victim and their families
		2.8 Participate and assist with community-based programs / activities / events that support Child Protection, Domestic & Family Violence, Sexual Assault and other related health promotion weeks	Hospital, Police, CHHS, All Cherbourg, AHW, Social Workers, youth services, schools, HAG	All Cherbourg involved in sexual assault awareness programs & events

3. Drugs, Alcohol & Violence

Goals	The Problems & Causes	Strategies	By Whom	Measurement
Break The Cycle: Reductions in deaths, violence, accidents, injuries and sickness. No Grog – No Worries. Increase community awareness of safe drinking practices.	**The Problems:** Alcohol Management Reform (AMR) Plan: alcohol seems to be worse since the implementation of AMR - increase in stealing, hold ups, ram raids, - increase in court appearance Lack of & inappropriate legal aid representation Drug and alcohol abuse and violence are "out of control" as a result of our history. Already high and increasing numbers of drug and alcohol users. Increases in death rate and users are starting and dying younger. Violence, alcohol abuse, family breakdown and loss of self image and control, sickness, allergies, loss of income, low self-esteem, poor hygiene and family break-ups. Affects total health (suicide, depression, stress, mental & physical health). Leaving the community to external rehabilitation centres prevents family visits. Accessing rehab can become costly	3.1 Establish Drug & Alcohol support group. 3.2 Establish Anger Management clinics or programs. 3.3 Elders to be introduced into schools as a regular thing, starting from prep, grade 1. 3.4 All AOD clients to be offered generalist – AODS counseling support services - to community, youth and families 3.5 To provide early intervention parenting specialist services to support families affected by substance misuse; children affected by FAS and other psychosocial issues 3.6 Increase liaison and networking with community & state police about volatile substance misuse. 3.7 Provide education and awareness programs on chroming, drugs and other substances – especially targeting youth.	AODS team; MH; social workers; psychologist; QPS & Justice Elders AODS team; ADFQ; Graham House; MH; social workers; psychologist EIPS; Social Worker; Child Health; AODS MH; Psychologist AODS & QPS & Justice AODS; CTC youth; justice; AODS; Hospital	AOD support group formed& established Anger management programs delivered Number of elders and visits to schools Promotion of resources / services available Number of community members accessing services Number of referrals received; families supported; Partnerships established between services Number of partnership programs delivered

	for families (e.g. rent, large family, food, etc...), most families can't afford it. Use of volatile substances (e.g.: 'chroming' and other drugs) is increasing – leading to depression and suicidal thinking. Parenting skills – kids turn into copy cats from a young age The Causes: History – past experience. State of mental health, low self-esteem. Family break-ups. Finances. Peer pressure – boredom, jobs, families. Lack of recreation.	3.8 Provide a detox service for community to access (inpatient / outpatient services) 3.9 To provide harm minimization and health promotion programs	AODS & Youth Services; Justice; Jumbunna	Number of patients accessing detox services Number of in-service training; community & schools programs Number of referrals received from QPS / Justice / Youth Services

4. a) Men's & Women's Business
4. b) Maternity, Children's & Youth Business

Goals	Problems & Causes	Strategies	By Whom	Measurement
To improve the general health and well being of Men & young boys / youth. To promote and increase physical activity / events and support healthier lifestyle choices To increase community's awareness of STIs and the long term effects / complications if not treated. Continue to work towards reducing number of follow ups and those needing treatment for STI's.	**4.1 Men's Business:** • Men's Group not functioning • Need for anger management training. • Sexually Transmitted Disease is a high priority. • Men, young boys / youth don't access health services or don't have enough regular health checks • **4.2 Women's Business** • Sexually Transmitted Disease is a high priority. • Not enough awareness and education of STIs around the community • Feel shame & embarrassed to seek treatment • Fearful of confidentiality problems.	**4.1 Men's Business** 4.1.1 Re-establish Men's Group & Mentoring Program 4.1.2 Run local anger management training/clinics. 4.1.3 Health Expo *(include: men's, women's, children & youth Health checks)* 4.1.4 Sporting Events (e.g. touch carnival, 3 on 3 basket ball, golf days, football, etc…) 4.1.5. Men's & youth healing camps (propose: x 2 camps per/year) 4.1.6 Continue STI follow ups and contact tracing **4.2 Women's Business** 4.2.1 Continue STI follow-ups & 'contact tracing' 4.2.2 Train AHW to assist with providing treatment(s) for STI's out in the community 4.2.3 Provide education and awareness of the seriousness of STI's 4.2.4 Reassure community not to feel shame and access treatment 4.2.5 Women and youth camp for girls *(strategies: 4.1.3 & 4.1.4 include women, young girls/youth)*	CCHS; Male health workers, Graham House, community services, youth services, schools, CCHS PCYC Cherbourg in partnership with other services CCHS, Hospital, Female HW's TAFE, educational	Number of Men's group meetings No. of anger management training or clinics provided. No. of participants/ attendance rate No. of health checks and referrals including treatment No. of follow ups and contacts and treatment provided No. of education sessions provided and to whom / groups No. of youth (girls) participating in events / activities AHW trained to

Goals	Problems & Causes	Strategies	By Whom	Measurement
The community wishes to document that it's first preference is to return birthing to Cherbourg as described in the Homelands Birthing Project. However, we acknowledge that this is not currently practical while midwives are not able to be recruited.	**4.3 Maternity** • AHW involvement in birthing and maternity services is limited. • Births are in Kingaroy – not Cherbourg. • Not enough antenatal follow ups and visit at pregnant women's homes • Mother's health & nutrition is less than satisfactory. • Young women may lack sufficient financial support or have no income to support them through their pregnancy • New mothers are young – and can lack knowledge of family planning, contraception, parenting skills, etc. • Post Natal Depression. • Kingaroy Birthing environment is not culturally inviting or sensitive . • Difficult for families to visit mothers in Kingaroy. • Transport to and from Kingaroy is a problem • Women not attend ultra-sound appointments	**4.3 Maternity** 4.3.1 AHW to be trained in maternity and birthing health checks / screenings 4.3.2 Recommence Alternative Birthing Reference Group and DOULA. 4.3.3 Provide education on unplanned pregnancy (encourage family planning) 4.3.4 Encourage young mothers to attend pre & post antenatal education sessions 4.3.5 More culturally appropriate classes for young mothers to help deal with babies when they go home (i.e. parenting, budgeting, cooking, hygiene) 4.3.6 More pre-birth nutrition education for mothers and education about Foetal Alcohol Syndrome (FAS). 4.3.7 Routine screening for post-natal depression. 4.3.8 Improve Kingaroy birthing environment / services to ensure it is welcoming and accommodating for women's cultural needs 4.3.8.1 Midwives from Kingaroy to visit community and provide outreach antenatal clinics in Cherbourg 4.3.9 Continue to promote SIDS awareness and provide support and counseling to parents and families 4.3.10 Educate community about risks of negative outcomes of pregnancies and SIDS and other related health problems . 4.3.11 Work to improve transport options and accessibility to services. 4.3.12 provide ultra-sound outreach services in local community	institutes, Midwife, Child Health Nurse CCHS, Hospital, Midwife, Child Health Nurse & AHWs (female) Kingaroy Midwives CCHS & hospital, management (EIPS) Social worker – counseling services, Other services and agencies Youth services Health services, Local & South Burnett Council CCHS, Hospital, Pop. Health, other com. services	provide adequate maternity and birthing care Improved health outcomes for pregnant women and bubs (birth weights) No. antenatal classes provided and No. of women attending sessions. Increased community awareness on pregnancy, nutrition, parenting, FAS, SIDS and other related health matters. Appropriate follow up care and counseling for post-natal depression Birthing suite more culturally appropriate / sensitive for women Improved access to services Increased community awareness of child health and related issues affecting childhood

Goals	Problems & Causes	Strategies	By Whom	Measurement
To improve health of babies and children To increase parents being involved in their children's health & education	**4.4 Child Health** • Nutrition: Introduce solids and cows milk too early (including soft drinks, lollies, cordials) • Hearing health problems • Learning difficulties (including: behavioural problems, FAS, etc...) • Respiratory problems • Skin problems (e.g. school sores, boils, scabies) • Head Lice • MRSA **4.5 Youth Business** Alcohol & yarndi causing neglect of children & young people. Lack of sufficient financial support	**4.4 Child Health** 4. 4.1 More education about breast feeding, nutrition – introducing foods / drinks to bubs; child health checks; managing childhood health problems (head lice, skin problems, MRSA, etc…); . 4.4.2 Screening of children for anaemia and advise on nutrition. 4.4.3 Provide positive parenting support programs to individuals and groups 4.4.4 Support community and school programs to reduce truancy / absenteeism. 4.4.5 Encourage parents to take child/ren to ENT clinic 4.4.6 Encourage parents to take child/ren to IROC clinic 4.4.7 Continue to facilitate the Cherbourg family play group **4.5 Young Peoples Business** 4.5.1 Refer to Strategies in 3 (Drugs, Alcohol & Violence) and 4.2 (Women's Business) and 4.4 (Child Health) 4.5.2 Encourage youth to attend school, seek support from local businesses to provide employment opportunities for youth	CCHS, Hospital, EIPS, child health team Schools; & other community organisations ENT, AHW, CCHS, schools EIPS; Graham House; Day Care Health services, Youth service, Local businesses, Council, Centre-link	development and behaviour No. of parenting programs provided & No. of participants attending Increased number of children attending school, decrease in number of children being suspended Increased number of parents attending clinics with child/ren / Number… attending play groups and education programs *As for above measurements* Increased youth completing high school & Increased employment of youth

Goals	Problems & Causes	Strategies	By Whom	Measurement
	Poor education, lack of employment opportunities			

5. Chronic Disease: Diabetes, Renal & Heart Disease

Goals	The Problems & Causes	Strategies	By Whom	Measurement
Early identification of diabetes. To reduce the number of people who suffer from complications of diabetes. In the longer term – to reduce the number of people with diabetes.	• Wasting time with fasting blood checks – clients unable to get early morning appointments. • Too much sugar & fat (fast foods). • People being overweight. • Lack of exercise. • Lack of awareness of diabetes and its prevention. • Poor food access, availability and food knowledge. • Too much sickness and too many deaths due to diabetes. • The problems are not often recognised and can be prevented and treated leading to increased quality of life. • Early deaths resulting from lack of awareness of renal disease. • Traveling for dialysis treatment takes it out of people/ stress • Lack of motivation to manage disease. • Lifestyle changes needed.	**5.1 Diabetes**: 5.1.1 Review timing of fasting blood checks and inform community about the procedures. 5.1.2 Establish better links between hospital, community health and BRMS to ensure continuity of care. 5.1.3 Increase and improve community designed health promotion resources. 5.1.4 Workplace screenings to continue **5.2 Renal:** 5.2.1 Provide opportunistic screening in hospital. 5.2.2 Provide continuity of support to carers. 5.2.3 Increase renal services and clinics in Cherbourg 5.2.4 Provide Renal Telehealth Clinics 5.2.5 Self Care dialysis training to be provided on community / kingaroy	CCHS Hospital Medicare locals PHN CRAICCHS Chronic disease team to coordinate Cherbourg Hospital CRAICCHS CCHS Kingaroy Renal & Toowoomba Renal Unit	Number of clients on register Number of clients on oral or needles medication Number of community awareness and education programs provided on chronic disease Establishment of telehealth clinics Decrease in travel for renal clients outside district

Goals	The Problems & Causes	Strategies	By Whom	Measurement
To reduce the number of people with Heart Disease (in the long term). To reduce the number of people who suffer from complications of heart disease. Early identification of heart disease.	**The Problem**: • Too much sickness and too many deaths due to heart disease. • The problems are not often recognised and can be prevented and treated leading to increased quality of life. **The Causes**: • Too much fat, salt and sugar. • People being overweight. • Lack of exercise. • Smoking and alcohol. • Poor food availability and food knowledge. • Lack of motivation to manage lifestyle changes needed.	**5.3 Heart Problems** 5.3.1 Promote healthy eating (Bush Tucker, Walkabouts, education, tasty cooking sessions, action on take-away and tuck-shops). 5.3.2 Promote healthy life-styles and personal goal setting. 5.3.3 Establish & promote exercise groups. 5.3.4 Education about Heart Disease. 5.3.5 Screenings - at all available opportunities. 5.3.6 Establish a register of clients with heart disease.	CRAICCHS CCHS & Hospital PHN; Schools; Youth Services; PCYC; Graham House;	Number of people participating in exercise & healthy eating programs. Increase in exercise of clients-self reported.
Raise community awareness about the causes, medication and prevention of asthma and other respiratory illness. Increase public knowledge with the aim of self management.	• Too much smoking in the homes • Babies and children exposed to too much smokes in small spaces • Too many colds and flu not be treated causing other lung problems • Homes not kept warm; too cold • Bushfires/rubbish/wood heaters and trees/flowers pollen • Hereditary. • Not enough information about the problems, treatment and causes.	**5.4 Respiratory** 5.4.1 Provide community awareness of smoking around children 5.4.2 Provide education to parents about using asthma sprays correctly on children 5.4.3 Increase promotion of signs of asthma and respiratory conditions 5.4.4 Encourage planting of native trees. 5.4.5 Education in schools, homes and family groups about breathing health.	Visiting Indigenous Respiratory Outreach Clinic (IROC); Hospital & CCHS; CRAICCHS PHN	Reduction of hospital admissions due to Asthma and Respiratory complaints. Number of clients on respiratory register; attending appointments Community Awareness Programs provided – Radio Promotion

	Wrong or substitutable medications. • Every-day environment (dust, flowers, sprays). • Incorrect diagnoses.			

5.1 Chronic Disease: Visiting Specialist / Allied Health Services

Goals	The Problems & Causes	Strategies	By Whom	Measurement
To encourage community to use the visiting specialist services in Cherbourg	**Problems/ Causes:** • not enough people using the services • family responsibilities • too many funerals (death) • lack understanding of importance of attending appointment • other commitments • Cancellations of appointments & clinics	**5.4 Visiting Specialist/ Allied Health** **Diabetes Specialist** **Podiatry** **Dietician/ Diabetes Educator:** **OT** **Speech** **Physio** **Oral Health** • Provide home visits, work with CCHS chronic disease team & Community Hospital Liaison Officers • Acknowledge cultural issues that impact on people not presenting for appointments	Visiting Specialist & Allied Health	Number of clinics provided & patients / clients attending clinics Number of clients with increased risk of complications

6. Ears (ENT) and Eye Health

Goals	The Problems & Causes	Strategies	By Whom	Measurement
To improve hearing and ear health in Cherbourg.	Children not learning – unable to understand and cannot hear properly because hearing problems are not being addressed. Parents not taking children to appointments & operations – going to Brisbane for weeks having a holiday	**6.1 Hearing Health** 6.1.1 Provide minor operations for hearing health on community 6.1.2 Conduct hearing tests early in the year focus on Year 1 students. 6.1.3 Follow-up children after ear operations.	CCHS & Cherbourg Hospital Deadly Ears; Schools; CRAICCHS	Decreased percentage of children referred for operations. Decreased percentage of children with ear problems.

Goals	The Problems & Causes	Strategies	By Whom	Measurement
Reduce hospital admissions from hearing health problems.	and children missing out on school. Parents neglecting children – ongoing ear problems lead to other health problems (eg : speech). Young children afraid of hearing screening tests. Not enough information given on why operation is needed and type of operation. No information given on risks during or after operation until pre-op. They may have to stay on an extra night and finding accommodation can be a problem. Information pamphlets only given out at pre-op. No immediate home visit or follow-up after ear operations. Post operative check-ups – clients sitting for hours just to spend 5 minutes with doctor. Late appointments mean spending another night in Brisbane, leading to more problems with accommodation and transport.	6.1.4 Frequent contact with High School – inform of any prior school students with hearing problems 6.1.5 Provide ongoing education programs in schools (e.g. exposure of hearing Screening equipment). 6.1.6 Improve information given to parents in sufficient time before operations. 6.1.7 Develop a pamphlet describing the whole process. 6.1.8 Conduct education with parents. 6.1.9 Local doctor to check-up after operations and confer with specialist by phone or tele health rather than returning to Brisbane.	CCHS & Cherbourg Hospital CRAICCHS Schools Deadly Ears Program	Increased percentage of clients referred for surgery having surgery completed. AHW skilling program developed and delivered. Review of advice & resources conducted. Pamphlet developed. Hospital & Telehealth follow-up's.
To provide eye health services	**6.2 Eye Health** Diabetes related eye problems. No Eye Health specialists visiting community. Drinking makes the problem worse.	**6.2 Eye Health** 6.2.1 Provide community awareness programs of eye health problems 6.2.2 Increase eye health access to services in the local community	CRAICCHS CCHS Visiting specialist	Number of referrals to eye health clinic; CRAICCHS & Opto-OPSM

7. Elderly & Aged Care

Goals	The Problems & Causes	Strategies	By Whom	Measurement
To provide quality health care to elderly and aging community members; especially those who still live alone at home (& with other family members) To provide regular home visits to elderly to prevent hospital admission in later stages of un-wellness	"Granny Burn Out" – grandparents caring for grandchildren and great grandchildren - Don't attend regular health checks, lack access to medical aids, poor medication management, - Limited / lack of support after discharge from hospitals - Lonely, isolated, overcrowding, not enough rest, - Lack appropriate access to food, transport, and other community facilities	7.1 Establish Elderly support groups 7.2 Establish Health Outreach Program for Elderly (HOPE) 7.3 Once a month gathering at Aged Care facility 7.4 Ensure relevant assessments are completed for elders who are at home 7.5 Link elders into appropriate services 7.6 Provide education on health matters relating to aged and elderly – increase community awareness on aging 7.7 Organize and support elders visits to the local aged care facility (i.e. to have catch up time with other elders in care) 7.8 Ramps and automatic door access for people with disabilities placed throughout community including Cherbourg Council; police station; court house, & other facilities that are difficult to access	All Cherbourg, community organisations and services CCHS, Hospital, CRAICCHS; Disability Qld, Council, Blue Care, Aged Care facilities, Respite Cherbourg Council and other services Disability Services Qld.	Elderly/ aged support group (Activities provided) Outreach program provided (No. of visits, assessments & outcomes) Referral Pathways established / developed Increased community awareness Facility/ies audit on disability access across community

8. Environmental Health

Goals	The Problems & Causes	Strategies	By Whom	Measurement
To encourage a healthy	**The Problems**: • No running water in creek	8.1 Council to enforce bi-law of two dog maximum per household & registrations	Cherbourg Council	Council to manage and enforce bi-laws

environment & community.	• Cattle traveling through • Horses in back yards • High cost of electricity • Dogs roaming • Wild Dogs in surrounding bush/ forestry area & dump • Our kids are sick from dogs / cats • Broken glass on streets / roads • Water ways and quality of water **Causes:** • Lack of community awareness - people being irresponsible about infectious conditions. • Poor nutritional condition, hygiene, housing and immunity. • Poverty, leading to poor and overcrowded living conditions (shared clothing, beds etc.). • People not taking proper precautions • Too many (mangy) dogs • Transport continues to be a big issue	8.2 Culling of wild dogs in bush / dump area 8.3 Ask Council to approach RSPCA regarding badly infected dogs in Cherbourg. 8.4 Provide education to sewage maintenance workers. 8.5 Council to provide Public Toilets / amenities in community 8.6 Approach Council to apply bi-laws to resolve broken glass problems and consider establishment of a recycling plant. 8.7 Run public education and courses at TAFE in hygiene and public health issues. 8.8 Investigate Murgon v. Cherbourg electricity bills; and ask Ergon to investigate supply and discuss with community. 8.9 More street lights in some streets; especially in areas where it is real dark (e.g. Bulgi & entry to Cherbourg along Barambah Ave) 8.10 Encourage households to filter and boil rainwater / town water – especially during floods 8.11 Flood water awareness programs on water quality through local media 8.12 Health Services to support parents to prevent swimming in creek 8.13 Disaster Management Group to provide updates to community and organisations/ services 8.14 Write to both Cherbourg and Murgon Councils seeking bike pathways between the towns.	Animal Control Cherbourg Council, CCHS, CRAICCHS Population Health Cherbourg Council TAFE; DDHHS population health Cherbourg Council; Ergon Cherbourg Council; CHHS; CRAICCHS; Population Health	Health Promotion fliers / letter drops activity recorded on animal control / care. Public Toilet facicilities available to community / visitors Decrease in glass injuries to ED Number of students enrolled / attendance at education sessions Education on energy saving strategies. Improved lighting Health Promotion activity recorded. Decrease in hospital presentation / admission due to water-borne illness

9. Cultural Appropriateness & Professionalism of Services

Goals	The Problems & Causes	Strategies	By Whom	Measurement

Cultural Appropriateness and Professionalism of Services.	**The Problem:**
	• Relationships between Aboriginal and Non-Aboriginal people.
	• Perceptions by some local people that
	  ○ People need to speak out more.
	  ○ Of two different standards of care (inequality).
	• Unhealthy Workplaces: lateral violence, bullying, gossip, judgemental, inappropriate, behaviours
	• Staff need to be culturally sensitive and aware
		9.1 Actively encourage managers and staff in the South Burnett (esp. Kingaroy OPD/ reception and maternity wards) to participate in Cultural Awareness and Learning Circle programs.
		9.2 Health Service to examine ways to have Indigenous Nursing Home clients returned home in end stage.
		9.3. Health Service to produce two booklets – Cultural Considerations and another on Communications & Language.
		9.4 CE / Executive Staff to encourage / assist boosting number attending Cultural Practice / Awareness Programs (CPP).
		9.5 Create healthy workplaces: provide resources and training to manage conflict within community organisations and services
			DDHHS CE, Executive and Line Managers (i.e. DON's / NUM's)
			HAG and CCHS
			DDHHS CE, Executive & Management
			CCHS, TAFE, counselors, schools
				80% South Burnett staff having completed training.
				Palliative Care Plan to include clients returning to Cherbourg.
				Brochures/booklets produced.
				Executive memo to all staff
				- percentage of attendance across district attended CPP
				Number of services participated in conflict management program

10. Development of the Cherbourg Health Services

Goal	The Problems & Causes	Strategies	By Whom	Measurement

Development of the Cherbourg Hospital and Community Health Service.	**The Problem:** • Not enough Health Workers qualified (especially locals). • Not enough Aboriginal Administration staff at the front of the hospital • Not enough Aboriginal nurses across the health service • TAFE to provide Certificates and diploma in Primary Health Care locally. • Lack of appropriate staff accommodation (local). • Staff at Cherbourg hospital lack awareness of community social health • Attitudes of hospital staff across health services can be rude and offensive – disrespectful – not very welcoming • Community lack knowledge and understanding of services provided by hospital (e.g. outpatients, emergency dept.)	10.1 TAFE to provide Primary Health Care education and training locally. 10.2 Encourage Aboriginal Health Worker to do further studies at University 10.3 Invite universities to promote programs/ courses they offer – Careers / NAIDOC week 10.4 Encourage more Aboriginal people to apply for local position within the Hospital / Community Health 10.5 Queensland Govt. Hospital & Health Services to provide local accommodation for visiting staff (i.e. nursing, doctors, allied health, health workers) 10.6 All Staff to attend cultural practice / awareness programs; and learn how to communicate appropriately & respectfully. 10.7 Educate community and other staff about health workers roles and responsibilities 10.8 Increase communities awareness of health services (e.g. CCHS; Hospitals & BRMS)	TAFE, Hospital & Health Services, Universities, DDHHS Management, HAG, CCHS Hospital DDHHS CHHS, CRAICCHS	Health Service Agreement / partnerships developed between key services / stakeholders. Qualified Health Workers in positions Local Accommodation available for visiting / casual staff 99% attendance within 12 months of commencement Decrease in presentation to hospital after hours / increase in outpatients

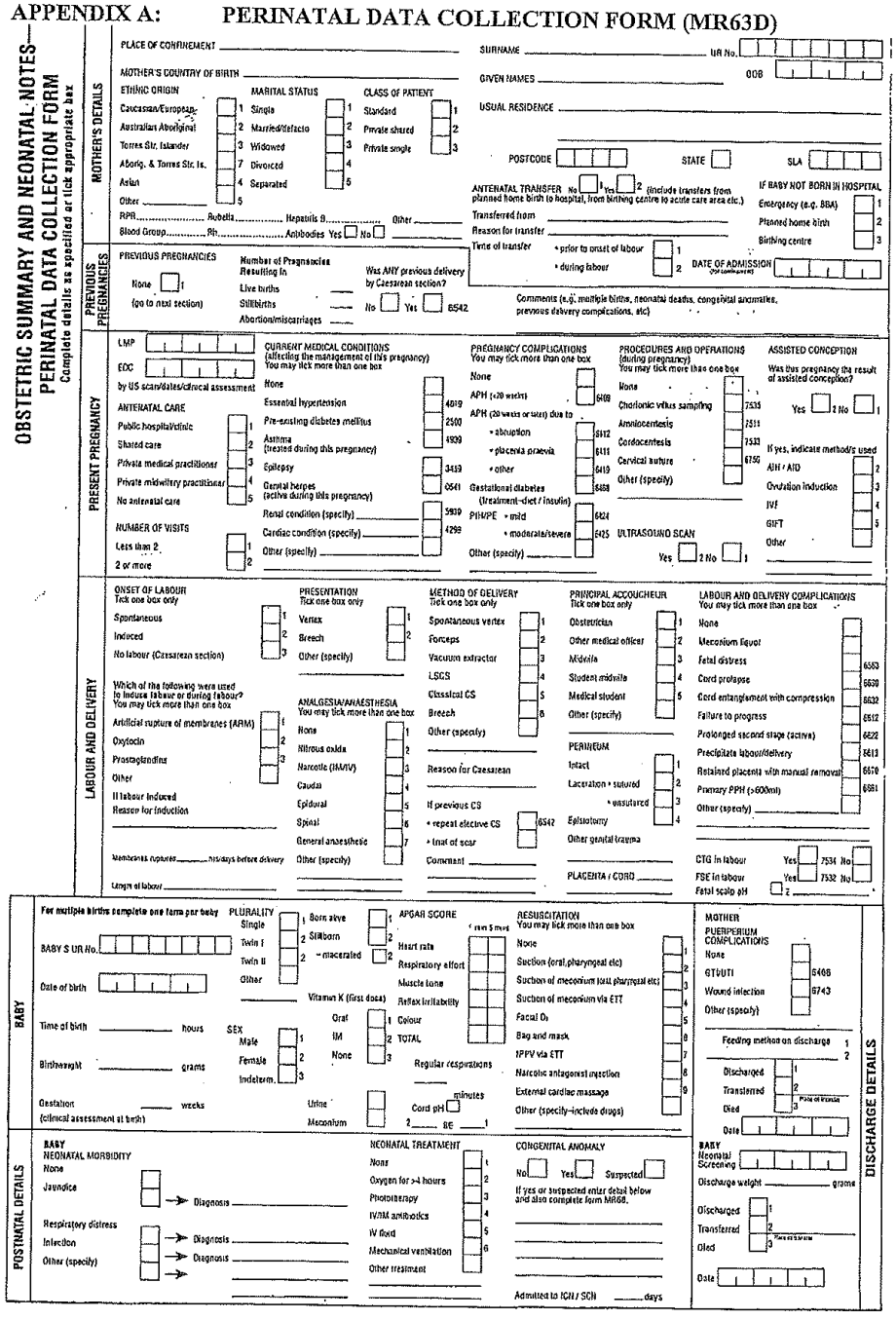
The following is the list of procedures which are recommended for application by AHWs when appropriately qualified:

Category	Application	Provises for AHWs
Injuries & Post Operative	Wound Dressing	Simple wounds only on a scale to be developed.
Sexual Health PCR Tests	Men – Swabs	Asymptomatic - by AHW Symptomatic - by other
PCR Tests	Women - Pap Smears	When qualified / When trained
Diabetes	Blood Sugar Levels	When trained
	Glucometers	When trained
Cardiovascular	Blood Pressures	When trained
	Weighing	When trained
Medications	(administering, monitoring)	When trained
	Scabies	When trained
	Head lice	When trained
	Tinea	When trained
	Boils	When trained
	Impetigo	When trained
	Worm treatments	When trained
Ears	Hearing/Ear Screening	When trained
	Drops	When trained
Eyes	Eye toilet/flush	When trained and when not related to object in eye
	Eye drops & ointment	When trained and when not related to object in eye
	Visual acuity	When trained
Lungs	Peak Flow Meter	When trained
	Puffers	When trained
	Spacers	When trained
General Health	First Aid	Annual First Aid Training
	Immunisation	When qualified
	Blood samples	When trained / qualified/ Endorsed
	Faeces/other samples	When trained
	Skin swabs (scabies, boils etc) Scabies & Boils follow-up	When trained
	Dressings	When trained
	Child Health Checks	When trained / skilled
Mental Health	Assessments / Data Entries	When trained/skilled When employed as MHW

** As identified in the Aboriginal& Torres Strait Islander Health Worker Career Structure and Competencies Standards*

21. Appendix 4

21.1. Perinatal Data Collection Form (MR63D)



APPENDIX A: PERINATAL DATA COLLECTION FORM (MR63D)

OBSTETRIC SUMMARY AND NEONATAL NOTES
PERINATAL DATA COLLECTION FORM
Complete details as specified or tick appropriate box

MOTHER'S DETAILS
PLACE OF CONFINEMENT
MOTHER'S COUNTRY OF BIRTH
ETHNIC ORIGIN: Caucasian/European 1; Australian Aboriginal 2; Torres Str. Islander 3; Aborig. & Torres Str. Is. 7; Asian 4; Other 5
MARITAL STATUS: Single 1; Married/defacto 2; Widowed 3; Divorced 4; Separated 5
CLASS OF PATIENT: Standard 1; Private shared 2; Private single 3
RPR ..... Rubella ..... Hepatitis B ..... Other
Blood Group ..... Rh ..... Antibodies Yes No
SURNAME ..... UR No.
GIVEN NAMES ..... DOB
USUAL RESIDENCE
POSTCODE STATE SLA
ANTENATAL TRANSFER No 1 Yes 2 (include transfers from planned home birth to hospital, from birthing centre to acute care area etc.)
Transferred from
Reason for transfer
Time of transfer • prior to onset of labour 1 • during labour 2
DATE OF ADMISSION
IF BABY NOT BORN IN HOSPITAL: Emergency (e.g. BBA) 1; Planned home birth 2; Birthing centre 3

PREVIOUS PREGNANCIES
PREVIOUS PREGNANCIES: None 1 (go to next section)
Number of Pregnancies Resulting In: Live births; Stillbirths; Abortion/miscarriages
Was ANY previous delivery by Caesarean section? No Yes 6542
Comments (e.g. multiple births, neonatal deaths, congenital anomalies, previous delivery complications, etc)

PRESENT PREGNANCY
LMP
EDC
by US scan/dates/clinical assessment
ANTENATAL CARE: Public hospital/clinic 1; Shared care 2; Private medical practitioner 3; Private midwifery practitioner 4; No antenatal care 5
NUMBER OF VISITS: Less than 2 1; 2 or more 2
CURRENT MEDICAL CONDITIONS (affecting the management of this pregnancy) You may tick more than one box
None; Essential hypertension 4019; Pre-existing diabetes mellitus 2500; Asthma (treated during this pregnancy) 4939; Epilepsy 3439; Genital herpes (active during this pregnancy) 0541; Renal condition (specify) 5939; Cardiac condition (specify) 4299; Other (specify)
PREGNANCY COMPLICATIONS You may tick more than one box
None; APH (<20 weeks) 6408; APH (20 weeks or later) due to • abruption 6412, • placenta praevia 6411, • other 6413; Gestational diabetes (treatment–diet / insulin) 6469; PIH/PE • mild 6424, • moderate/severe 6425; Other (specify)
PROCEDURES AND OPERATIONS (during pregnancy) You may tick more than one box
None; Chorionic villus sampling 7535; Amniocentesis 7511; Cordocentesis 7533; Cervical suture 6755; Other (specify)
ASSISTED CONCEPTION
Was this pregnancy the result of assisted conception? Yes 2 No 1
If yes, indicate method/s used: AIH / AID 2; Ovulation induction 3; IVF 4; GIFT 5; Other
ULTRASOUND SCAN Yes 2 No 1

LABOUR AND DELIVERY
ONSET OF LABOUR Tick one box only: Spontaneous 1; Induced 2; No labour (Caesarean section) 3
Which of the following were used to induce labour or during labour? You may tick more than one box: Artificial rupture of membranes (ARM) 1; Oxytocin 2; Prostaglandins 3; Other
If labour induced Reason for induction
Membranes ruptured ..... hrs/days before delivery
Length of labour
PRESENTATION Tick one box only: Vertex 1; Breech 2; Other (specify)
ANALGESIA/ANAESTHESIA You may tick more than one box: None 1; Nitrous oxide 2; Narcotic (IM/IV) 3; Caudal 4; Epidural 5; Spinal 6; General anaesthesia 7; Other (specify)
METHOD OF DELIVERY Tick one box only: Spontaneous vertex 1; Forceps 2; Vacuum extractor 3; LSCS 4; Classical CS 5; Breech 6; Other (specify)
Reason for Caesarean
If previous CS • repeat elective CS 6542 • that of scar
Comment
PRINCIPAL ACCOUCHEUR Tick one box only: Obstetrician 1; Other medical officer 2; Midwife 3; Student midwife 4; Medical student 5; Other (specify)
PERINEUM: Intact 1; Laceration • sutured 2 • unsutured 3; Episiotomy 4; Other genital trauma
PLACENTA / CORD
LABOUR AND DELIVERY COMPLICATIONS You may tick more than one box: None; Meconium liquor 6553; Fetal distress 6630; Cord prolapse 6632; Cord entanglement with compression 6512; Failure to progress 6522; Prolonged second stage (active) 6613; Precipitate labour/delivery 6570; Retained placenta with manual removal 6581; Primary PPH (>600ml); Other (specify)
CTG in labour Yes 7534 No
FBE in labour Yes 7532 No
Fetal scalp pH 2

BABY
For multiple births complete one form per baby
BABY'S UR No.
Date of birth
Time of birth ..... hours
Birthweight ..... grams
Gestation ..... weeks (clinical assessment at birth)
PLURALITY: Single 1; Twin I 2; Twin II 2; Other
SEX: Male 1; Female 2; Indeterm. 3
APGAR SCORE: 1 min 5 min 10 min
Born alive 1; Stillborn 2; • macerated 2
Heart rate; Respiratory effort; Muscle tone; Reflex irritability; Colour; TOTAL
Regular respirations
Vitamin K (first dose) Oral 1; IM 2; None 3
Urine; Meconium
Cord pH ..... minutes 2 ..... BE 1
RESUSCITATION You may tick more than one box: None; Suction (oral,pharyngeal etc); Suction of meconium (oral,pharyngeal etc); Suction of meconium via ETT; Facial O2; Bag and mask; IPPV via ETT; Narcotic antagonist injection; External cardiac massage; Other (specify–include drugs)

MOTHER
PUERPERIUM COMPLICATIONS: None; GTI/UTI 6408; Wound infection 6743; Other (specify)
Feeding method on discharge 1 2
Discharged 1; Transferred 2 (Place of transfer) 3; Died
Date

POSTNATAL DETAILS
BABY
NEONATAL MORBIDITY: None; Jaundice → Diagnosis; Respiratory distress; Infection → Diagnosis; Other (specify) → Diagnosis
NEONATAL TREATMENT: None; Oxygen for >4 hours; Phototherapy; IV/IM antibiotics; IV fluid; Mechanical ventilation; Other treatment
CONGENITAL ANOMALY: No Yes Suspected
If yes or suspected enter detail below and also complete form MR68.
Admitted to ICN / SCN ..... days

DISCHARGE DETAILS
BABY
Neonatal Screening
Discharge weight ..... grams
Discharged 1; Transferred 2 (Place of transfer) 3; Died
Date

22. Appendix 5

22.1. Congenital Anomaly Form (MR66)

CONGENITAL ANOMALY FORM (MR66)

MOTHER'S DETAILS

MR 66

NEONATAL NOTES—CONGENITAL ANOMALY/MORBIDITY DATA

To be completed for anomaly or morbidity found within the first 28 days after birth.
Complete one form per baby.

HOSPITAL .....

UR No.

MOTHER'S USUAL ADDRESS .....

Date of Birth

.....

BABY'S DETAILS

Baby's UR No. Date of Birth

SEX
Male
Female
Indeterm

Born alive
Not born alive

PLURALITY: Single
Twin I
Twin II
Other (specify) .....

A. Full description of all anomalies present or suspected (including those not able to be illustrated on the diagrams below). If anomaly suspected indicate this by an 's' in brackets after anomaly description.

.....

.....

.....

.....

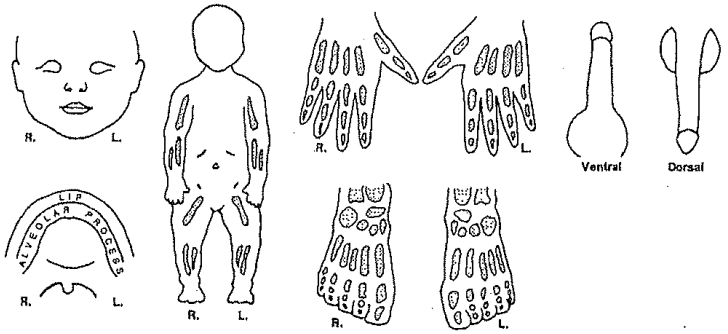
.....

.....

.....

.....

B. Indicate by shading or marking the appropriate diagram(s) the anatomical site(s) affected by congenital anomaly(ies).



C. NEONATAL MORBIDITY (extra details)

.....

.....

.....

.....

.....

.....

Medical Practitioner's Signature .....

Surname (BLOCK LETTERS) .....

Designation ..... Date / /

Regulation 4 (2) (a) of the Perinatal Statistics Regulations 1985 provides that this Return must be forwarded within 35 days of the birth of the baby.

Forward to:
DIRECTOR-GENERAL OF HEALTH AND MEDICAL SERVICES,
(Attention Chief Statistician)
G.P.O. Box 48, Brisbane, 4001.

E-182 "2085—Govt Printer, Qld"

23. Appendix 6

23.1. Obstetric Risk Assessment Form (Qld Health)

Maternal Age:

Less than 20	1
20-29	0
30-34	1
35 or more	2

Parity:

0	1
1-2	0
2	1
4 or more	2

Social Factors:

Family Income	
Entirely Social Security	1
Unsupported Mother (No Stable union)	1

Past Obstetric Performance:

Stillbirth	4
Neonatal Death	4
Preterm Birth (>34 weeks)	2
Low Birth Weight Infant (<2500g)	2
2 or more Terminations	2
Caesarean Sections	4
Antepartum Haemorrhage	4
Postpartum Haemorrhage	4

Past or Present Medical History:

Established Diabetes	4
Gestational Diabetes	2
Cardiac Disease	4
Chronic Respiratory Disease	4
Chronic Renal Disease	4
Recurrent UTI's	1
Endocrine Disease	4
Anaemia (Hb<100g/dL)	2
Blood Group Antibodies	2
Cervical Cone Biopsy	4

Present Pregnancy:

Height <157.5cm (63")	1
Weight >90 kgs	1
Weight <50 kgs	1
Smokes 5 cigs or more/day	2
Drinks Alcohol more than 1 drink twice weekly	1
Multiple Pregnancy	4
Breech after 34 weeks	4
Vaginal bleeding after 13 weeks gestation	2
Blood Pressure	
140+/90+ before 20 weeks	4
140+/90+ after 20 weeks	2
160+/100+	4

Score At First Visit …….

Score at 34 weeks …….

High Risk = 8 or more
Medium Risk = 3 or more
Low risk = 0 to 2
A Risk Score Less than 8 Does Not Indicate An Absence of Risk

Reference/Source: (Queensland Government, 2016)

24. Appendix 7

24.1. Obstetric Risk Assessment Sheet (A)

RISK FACTORS FOR WOMEN WHO HAVE BEEN REMOVED FROM CHERBOURG TO KINGAROY OVER THE PAST FIVE YEARS.

ID NO ……

YEAR: ……..

Place of Birth for baby: ……..

MOTHERS DETAILS:

Age: ……..

Indigenous Status

Aboriginal	Yes	No
Torres Strait Islander	Yes	No
Aboriginal and TI	Yes	No
Not Aboriginal or TI	Yes	No

Marital status

Sole Parent		
Never married		
Married/defacto		
Widowed		
Divorced		
Seperated		

Parity: ……

MEDICAL HISTORY

(a) History of the following Neurological diseases:

Epilepsy	Yes	No
Multiple Sclerosis	Yes	No
Subarachnoid Haemorrhage	Yes	No

(b) History of the following Medical disorders:

Tuberculosis	Yes	No
Asthma	Yes	No
Cardiac disorders	Yes	No
Thrombo-embolism	Yes	No
Clotting disorders	Yes	No
Nephropathy	Yes	No
Diabetes Mellitus	Yes	No
Addison's disease	Yes	No
Cushing's disease	Yes	No
Hypthyroidism	Yes	No
Hyperthyroidism	Yes	No
Crohn's disease	Yes	No
Group B strep	Yes	No
Vaginal swab	Yes	No
PCR	Yes	No
Tobacco (cigarette smoking)	Yes	No
Alcohol	Yes	No
Drugs	Yes	No
STI's	Yes	No
GCT	Yes	No
Anaemia <6,0 mmol/L	Yes	No

(c) History of the following gynecological disorders:

Vaginal prolapse	Yes	No
Conization of the cervix	Yes	No
Myomectomy, subserous fibromyoma	Yes	No
Myomectomy, submucous or intramural fibromyoma	Yes	No
Vesicovaginal fistula	Yes	No
Rectovaginal fistula	Yes	No
Abnormal cervical cytology	Yes	No
In case of carcinoma	Yes	No
DES-esposed in utero	Yes	No
IUD in situ	Yes	No
Infertility	Yes	No
Pelvic Fracture	Yes	No
Meconium staining of Liquor	Yes	No

25. Appendix 8

25.1. Revised International Obstetric Risk Form (B)

Categories of Risk for Midwifery Clients

Categories of risk are subjective and fluid rather than fixed and different approaches to risk categorisation are appropriate in different contexts. In this light an alternative categorisation to the one used by Qld State Health is examined for its applicability to indigenous community setting.

The committee classifies women with one or more risk factors to one of the following groups:

GROUP A: The woman will receive primary care (from the midwife), the confinement may take place at home or in the hospital.

GROUP B: The woman will be referred to the obstetrician for consultation. After his or her advice, the midwife and woman will decide on subsequent care. The consultation may lead to a decision for hospital delivery under the care of midwife.

GROUP C: The woman will be referred to the obstetrician for secondary care: confinement takes place in hospital

RISK FACTORS AND THE ASSIGNMENT TO ONE OF THE GROUPS A, B, OR C

(1) MEDICAL HISTORY

(a) History of the following *Neurologic* disease

Epilepsy, subarachnoid haemorrhage, multiple sclerosis	B

(b) History of the following *Medical* disorders

Tuberculosis	C
Bronchial Asthma	B
Cardiac disorders	B
Thrombo-embolism	B
Clotting disorders	C
Nephropathy	B
Diabetes Mellitus	C
Addison’s disease, Cushing’s disease	C
Hypothyroidism	B

Hyperthyroidism	C
Anaemia, <6.0 mmol/L	B
Colitis ulcerosa, Crohn's disease	C

(c) History of the following *Gynecological* disorders

Vaginal prolapse	B
Conization of the cervix	C
Myomectomy, subserous fibromyoma	A
Myomectomy, submucous or intramural fibromyoma	C
Vesicovaginal or rectovaginal fistula	C
Abnormal cervical cytology	A
In case of carcinoma	C
DES-exposed in utero *(daughters of DES)*	A
IUD in situ	A
Infertility	A
Pelvic Fracture	B
Use of hard drugs	C
Psychiatric disorders	B

(2) Obstetric history

Rhesus sensitisation	C
Pregnancy hypertension	A
Recurrent abortion in first trimester	A
Cervical incompetence	C
Abruptio placentae	C
Forceps of vacuum extraction	A
Caesarean section	C
Fetal growth retardation	C
Neonatal asphyxia	B
Fetal death	B
Neonatal death	B
Congenital malformation	B
Postpartum haemorrhage	B
Manual removal of placenta	B
Third-degree perineal tear	A
Puerperal psychosis	A
Symphysiolysis	A
Age of nulliparous woman over thirty-five years	B
Age of multiparous woman over forty years	B
Age under fifteen years	A
Grand multiparity	A

(3) Abnormalities orginating during antenatal period

Anemia, Hb <6.0 mmol/L	B
Pyelitis	A
Rubella, cytomegaly	A
Toxoplasmosis	C
Herpes simplex	B
Hernia nuclei pulposi, originating during pregnancy	B
Abnormality of cervical cytology	A
Use of hard drugs	C
Psychiatric disorders	B
Amniocentesis or chorionic villus biopsy	A
Suspicion of foetal malformation	B
Hypertension, diastolic greater than ninety-five	B
Proteinuria	B
Rhesus sensitisation	C
Haemorrhage after twenty weeks	C
Abruptio placentae	C
Suspicion of foetal growth retardation	B or
Post-maturity	C
Imminent preterm labour	C
Cervical incompetence	C
Multiple pregnancy	C
Malposition of the foetus	B or C
Disproportion in the third trimester	B
Fetal death	B or C

(4) Abnormalities during labor and delivery

Malposition of the fetus	C
Signs of foetal distress	C
Ruptured membranes without contractions (>24hrs)	C
Poor progress of labour or delivery	C
Abnormal haemorrhage during labor	C
Abruptio placentae	C
Vasa previa	C
Excessive haemorrhage during the third or fourth period	C
Retained placenta	C
Third-degree perineal tear	C
Complicated perineal tear	C

(5) Abnormalities during the puerperium

(for specialists MEDICAL or PAEDIATRIC care in hospital)

1. **For the mother:** vulval hematoma, serious puerperal infection, puerperal psychosis, thrombo-embolic disease.

2. **For the baby:** growth retardation or preterm birth, cyanosis, hypothern-da, serious congenital malformations, severe jaundice or jaundice in the first twenty-four hours.